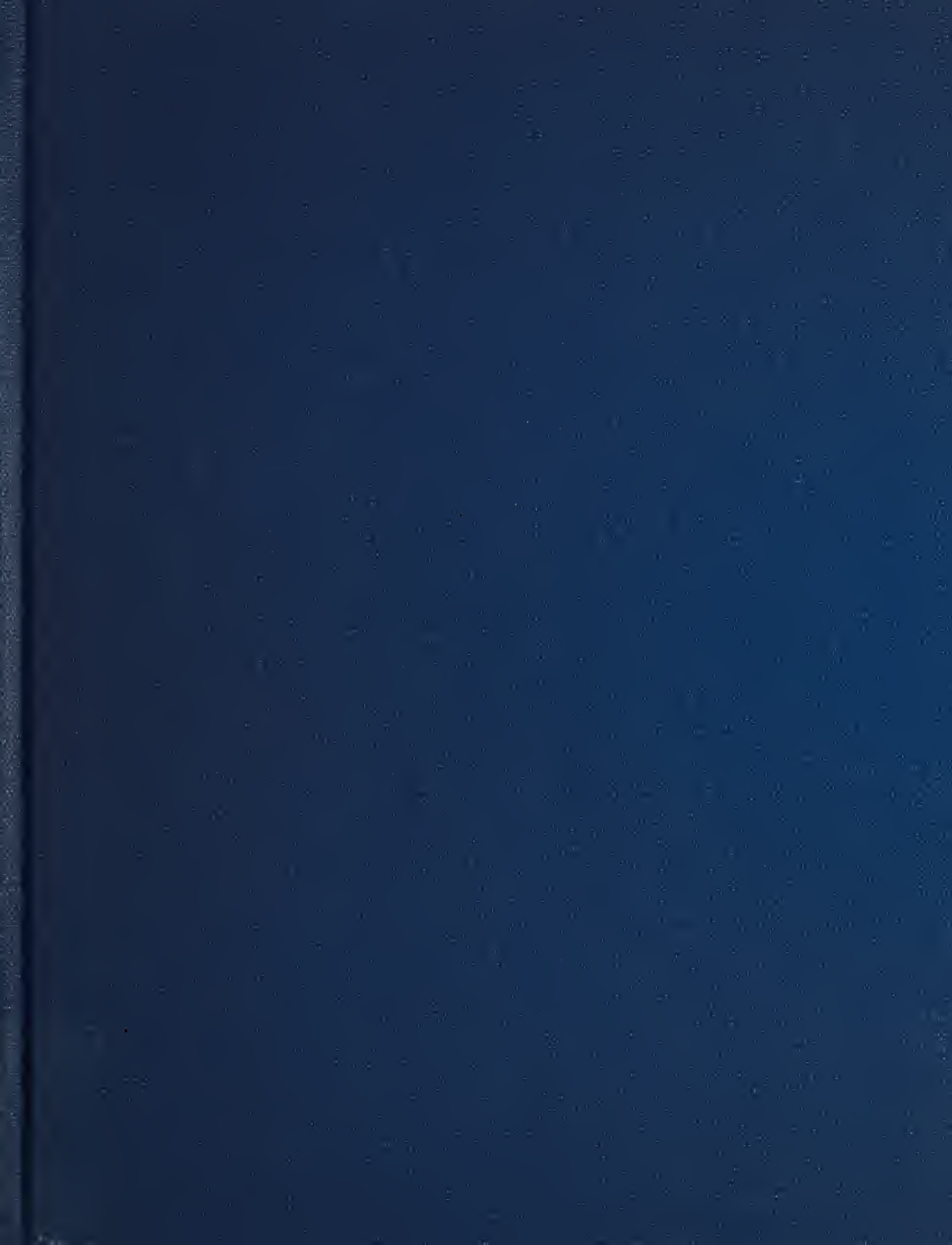




The Bancroft Library

University of California • Berkeley

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III

Eric Dibner

ADVOCATE AND SPECIALIST IN ARCHITECTURAL ACCESSIBILITY

Hale Zukas

NATIONAL DISABILITY ACTIVIST: ARCHITECTURAL AND
TRANSIT ACCESSIBILITY, PERSONAL ASSISTANCE SERVICES

Interviews Conducted by
Kathy Cowan
and Sharon Bonney
1997-1998

Since 1954 the Regional Oral History Office has been interviewing leading participants in or well-placed witnesses to major events in the development of Northern California, the West, and the Nation. Oral history is a method of collecting historical information through tape-recorded interviews between a narrator with firsthand knowledge of historically significant events and a well-informed interviewer, with the goal of preserving substantive additions to the historical record. The tape recording is transcribed, lightly edited for continuity and clarity, and reviewed by the interviewee. The corrected manuscript is indexed, bound with photographs and illustrative materials, and placed in The Bancroft Library at the University of California, Berkeley, and in other research collections for scholarly use. Because it is primary material, oral history is not intended to present the final, verified, or complete narrative of events. It is a spoken account, offered by the interviewee in response to questioning, and as such it is reflective, partisan, deeply involved, and irreplaceable.

This manuscript is made available for research purposes. All literary rights in the manuscript, including the right to publish, are reserved to The Bancroft Library of the University of California, Berkeley. No part of the manuscript may be quoted for publication without the written permission of the Director of The Bancroft Library of the University of California, Berkeley.

Requests for permission to quote for publication should be addressed to the Regional Oral History Office, 486 Library, University of California, Berkeley 94720, and should include identification of the specific passages to be quoted, anticipated use of the passages, and identification of the user.

It is recommended that this oral history be cited as follows:

To cite the volume: *Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III*, an oral history conducted in 1997-1998, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000.

To cite an individual interview: [ex.] Hale Zukas, "National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services," an oral history conducted in 1997 by Sharon Bonney in *Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000.

Copy no. 1

Cataloging information

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY.
Volume III, 2000, xxii, 209 pp.

Eric Dibner (b. 1947), *Advocate and Specialist in Architectural Accessibility*: attendant work for Scott Sorenson, John Hessler, and Hale Zukas; activism on Berkeley campus and within Rolling Quads; Physically Disabled Students' Program and Center for Independent Living: advocacy for assistive technology, removal of architectural barriers, accessible housing and peer counseling; reflections on independent living issues, environmental disability; disability compliance officer, city of Berkeley, 1990s. Hale Zukas (b. 1943), *National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services*: growing up with cerebral palsy; UC Berkeley student, 1966-1971; impact of power wheelchair on independent living skills; community affairs coordinator at Center for Independent Living; establishment of In-Home Support Services; San Francisco and Washington, D.C. 504 sit-in, 1977; Federal Architectural and Transportation Compliance Board, 1980-1983; advocacy for an accessible BART, 1975-1977; necessity of learning mobility skills.

Interviews conducted in 1997-1998 by Kathryn Cowan and Sharon Bonney for the Disability Rights and Independent Living Movement Oral History Series, Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

ACKNOWLEDGMENTS

The Disability Rights and Independent Living Movement Oral History Series was funded primarily by a three-year field-initiated research grant awarded in 1996 by the National Institute on Disability and Rehabilitation Research (NIDRR), an agency of the United States Department of Education, Office of Special Education and Rehabilitative Services. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agency.

Special thanks are due to other donors to this project over the years: the Prytanean Society; Raymond Lifchez, Judith Stronach, and Dr. Henry Bruyn; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project.

TABLE OF CONTENTS--Builders and Sustainers of the Independent Living
Movement in Berkeley, Volume III

SERIES INTRODUCTION by Simi Linton	i
SERIES HISTORY by Ann Lage and Susan O'Hara	vii
SERIES LIST	xiv
INTERVIEW WITH ERIC DIBNER <i>Advocate and Specialist in Architectural Accessibility</i>	xix
Table of Contents	xx
INTERVIEW WITH HALE ZUKAS <i>National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services</i>	92
Table of Contents	93
TAPE GUIDE	198
INDEX	200

SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbs on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been

time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

Simi Linton, Ph.D., Co-Director
Disability Studies Project
Hunter College

New York, New York
April 1999

SERIES HISTORY--The Disability Rights and Independent Living Movement
Oral History Project, by Ann Lage and Susan O'Hara

Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The

personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C, was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to

other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator
Susan O'Hara, Historical Consultant

Regional Oral History Office
The Bancroft Library
University of California, Berkeley
September 1999

August 2000

Disability Rights and Independent Living Movement Oral History Series
The Formative Years in Berkeley, California

Single-interview volumes

- Mary Lou Breslin, *Cofounder and Director of the Disability Rights Education and Defense Fund, Movement Strategist, 2000.*
- Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis, 2000.*
- Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000.*
- Charles Grimes, *Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967-1990s, 2000.*
- Deborah Kaplan, *National Policy Advocate and Leader of Disability Rights Organizations, 1976-1990s, 2000.*
- Johnnie Lacy, *Director, Community Resources for Independent Living: An African-American Woman's Perspective on the Independent Living Movement in the Bay Area, 1960s-1980s, 2000.*
- Joan Leon, *Administrator at Berkeley's Center for Independent Living and the California Department of Rehabilitation, Cofounder of the World Institute on Disability, 2000.*
- Susan O'Hara, *Director of the UC Berkeley Disabled Students' Program, 1988-1992, Coordinator of the Residence Program, 1975-1988, and Community Historian, 2000.*
- Corbett O'Toole, *Advocate for Disabled Women's Rights and Health Issues, Founder of Disabled Women's Alliance, 2000.*
- Zona Roberts, *Counselor for UC Berkeley's Physically Disabled Students' Program and the Center for Independent Living, Mother of Ed Roberts. Appended: Jean Wirth, Counselor at the College of San Mateo and Early Mentor to Ed Roberts, 2000.*
- Susan Sygall, *Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues, 2000.*

In Process, single-interview volumes:

Judy Heumann, Deputy director of the Center for Independent Living, cofounder of the World Institute on Disability, assistant secretary of the U.S. Department of Education. (in process)

Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

Pat Wright, Director, Governmental Affairs Office of the Disability Rights Education and Defense Fund, strategist for the Americans with Disabilities Act. (in process)

Multi-interview volumes:

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S INDEPENDENT LIVING MOVEMENT, 2000.

Edward V. Roberts, *The UC Berkeley Years: First Student Resident at Cowell Hospital, 1962.*

James Donald, *Student Resident at Cowell, 1967-1968, Attorney and Deputy Director of the California Department of Rehabilitation, 1975-1982.*

Cathrine Caulfield, *First Woman Student in the Cowell Program, 1968.*

Herbert R. Willsmore, *Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center For Independent Living, 1975-1977.*

Billy Charles Barner, *First African American Student in the Cowell Program, 1969-1973, Administrator in Disability Programs in Los Angeles.*

John "Jack" Rowan, *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982.*

Peter Trier, *Student at Berkeley: Transition from the Cowell Hospital Program to the Residence Halls, 1975.*

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM: KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS, 2000.

Henry Bruyn, *Director, Student Health Services, 1959-1972.*

Edna Brean, *Nurse Coordinator, Cowell Residence Program, 1969-1975.*

Lucile Withington, *Department of Rehabilitation Counselor, Cowell Residence Program, 1969-1971.*

Karen Topp Goodwyn, *Department of Rehabilitation Counselor in Berkeley, 1972-1983.*

Gerald Belchick, *Department of Rehabilitation Counselor, Liaison to the Cowell Program, 1970s.*

John Velton, *Department of Rehabilitation Administrator: Providing Oversight for the Residence Program, Fostering Career Placement and Computer Training, 1970s-1980s.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY VOLUME I, 2000.

Herbert Leibowitz, *Research and Training Specialist for the Rehabilitation Services Administration, 1971-1990.*

Mary Lester, *Grant Writer for the Early Center for Independent Living in Berkeley, 1974-1981.*

Bette McMuldren, *Assistant to Judy Heumann and Grant Writer at the Center for Independent Living, 1975-1980.*

Kenneth Stein, *Public Information Coordinator for the Center for Independent Living and Participant/Observer of the Disability Movement.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II, 2000.

Carol Fewell Billings, Attendant and Observer in the Early Days of the Physically Disabled Students' Program and the Center for Independent Living, 1969-1977.

Michael Fuss, Attendant for Cowell Residents, Assistant Director of the Physically Disabled Students' Program, 1966-1972.

Linda Perotti, An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III, 2000.

Eric Dibner, Advocate and Specialist in Architectural Accessibility.

Hale Zukas, National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV, 2000.

Janet Brown, Student Member of the National Federation of the Blind and First Newsletter Editor for the Center for Independent Living, 1972-1976.

Phil Chavez, Peer Counselor at the Center for Independent Living, 1970s-1990s.

Frederick C. Collignon, UC Professor of City and Regional Planning: Policy Research and Funding Advocacy.

Hal Kirshbaum, Director of Peer Counseling at the Center for Independent Living.

Michael Pachovas, Berkeley Political Activist, Founder of the Disabled Prisoners' Program.

Raymond "Ray" Uzeta, Independent Living Centers in Berkeley, San Francisco, and San Diego: Perspective on Disability in Minority Communities.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V, 2000.

Jacquelyn Brand, *Parent Advocate for Independent Living, Founder of the Disabled Children's Computer Group and the Alliance for Technology Access.*

Doreen Pam Steneberg, *Parent Advocate for Educational Rights for Children with Disabilities.*

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS, 2000.

Cynthia Jones, *Mainstream Magazine Editor and Publisher.*

William Stothers, *Journalist and Managing Editor of Mainstream Magazine.*

UNIVERSITY ADMINISTRATORS RECALL ORIGIN OF THE PHYSICALLY DISABLED
STUDENTS' RESIDENCE PROGRAM, 1987.

Arleigh Williams, *Recollections of the Dean of Students.*

Betty H. Neely, *Recollections of the Director of Student Activities and Programs.*

In Process, multi-interview volumes:

Neil Jacobson, *Cofounder of the Computer Training Project and Cochair of the President's Committee on Employment of People with Disabilities.*

Scott Luebking, *Cofounder of the Computer Training Project, Specialist in Accessible Technology. (in process)*

Maureen Fitzgerald, *Early Deaf Services Programs at the Center for Independent Living. (in process)*

Anita Baldwin, *Deputy Director of the Center for Independent Living, Early 1980s: Observations of Blind Services and Staff Strike. (in process)*

Joanne Jauregui, *Activist in the Deaf Community: Deaf Services at Center for Independent Living. (in process)*

VIDEOTAPED INTERVIEWS:

Mary Lou Breslin, Kitty Cone, Neil Jacobson, Joanne Jauregui, Deborah Kaplan, Johnnie Lacy, Joan Leon, Susan O'Hara, Zona Roberts, Ken Stein, Herb Willsmore, Hale Zukas.

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

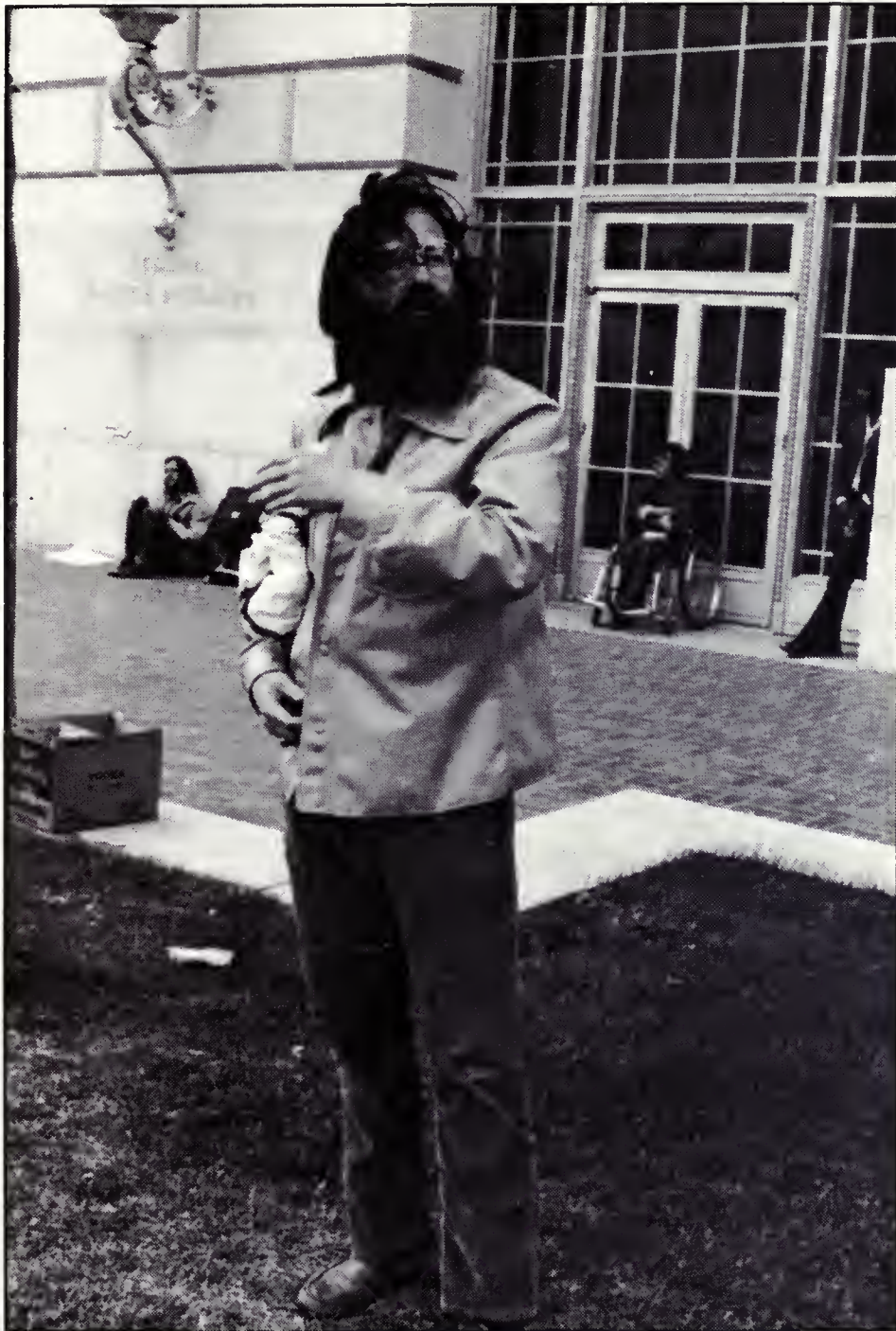
Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III

Eric Dibner

ADVOCATE AND SPECIALIST IN ARCHITECTURAL ACCESSIBILITY

An Interview Conducted by
Kathy Cowan
in
1998



Eric Dibner at the sit-in in the Federal Office Building in San Francisco, 1977.



Eric Dibner, accessibility specialist for Alpha One in Maine, 1986-1991.

TABLE OF CONTENTS--Eric Dibner

	INTERVIEW HISTORY	xxi
	BIOGRAPHICAL INFORMATION	xxii
I	ATTENDANT WORK IN THE COWELL HOSPITAL RESIDENCE PROGRAM, 1967-1968	1
	Youth in Florida, Maine, and Southern California; Enrolling at Berkeley	1
	First Jobs as an Attendant to Scott Sorenson and John Hessler	3
	The Countercultural Scene in Berkeley: Questioning Authority	4
	Cowell Hospital Setting	7
	Residents, Staff, and the Social Milieu at Cowell	9
	Attendant Work	11
	The Rolling Quads: Disability Identity and Activism	13
	Ten Months in France with John Hessler	16
II	THE BERKELEY SCENE AND THE PHYSICALLY DISABLED STUDENTS' PROGRAM [PDSP]: DEVELOPING THE INDEPENDENT LIVING MODEL, 1969-1972	18
	Attendant for Scott Sorenson Again: Rent Strike, Scott's Death	18
	Outside the Mainstream	22
	Accessible Housing, Curb Ramps, Assistive Technology	22
	PDSP, House on a Truck, and the Roberts' Green House	27
	Hanging Out in Berkeley: The Food Conspiracy and Other Alternative Directions	31
	A Little Bit of Everything at PDSP, 1971-1972	33
	Campus Committee for Removal of Architectural Barriers	34
	The People and Atmosphere at PDSP	36
	Peer Counseling	39
	Components of the Independent Living Model	39
	Self-Directed Attendant Services	40
III	CENTER FOR INDEPENDENT LIVING IN BERKELEY, 1973-1982	45
	Genesis of CIL	45
	Working on City of Berkeley's Housing Committee, 1973	48
	Attendant for Hale Zukas, 1974	49
	Going to Work for CIL, Spring 1975	52
	Growth and Commitment at CIL	53
	Struggle for an Egalitarian Structure	55
	Securing Funding for CIL's Housing Department	63
	Access Issues: The Opera House and the Grocery Stores	64
	Marilyn Golden and Access California	66
	Spin-Offs from CIL: Organizing a Movement	67
IV	WORKING ON DISABILITY ISSUES IN MAINE, NEW MEXICO, AND BERKELEY, 1985-1999	73
	Seeking a New Life in Maine	73
	Working for an Independent Living Program in Maine	74
	Reflections on the ADA	77
	Differences between Maine, New Mexico, and Berkeley	80
	Environmental Illness: Broadening the Definition of Disability	83
	Disability Compliance Coordinator for the City of Berkeley, 1996-	84
	Final Thoughts	88

INTERVIEW HISTORY--Eric Dibner

Eric Dibner was invited to participate in the Disability Rights and Independent Living Movement Series because of his intimate involvement with all aspects of the early development of the Physically Disabled Students' Program and the Center for Independent Living. He was an observer of and participant in the development of the movement from 1967 to 1985. Because of his experiences as an attendant, a student, and a resident of Berkeley, as well as his work on disability issues at PDSP and CIL, his interview offers a unique perspective on the movement, participants, organizations, and issues.

In his interview, Mr. Dibner recounts his memories of the earliest days of the Cowell Hospital program and his friendships with John Hessler, Ed Roberts, and many of the leaders of the fledgling independent living movement. He recalls his experiences as an attendant for Scott Sorenson, John Hessler, and Hale Zukas, and describes the events and discussions that led to the development of PDSP and CIL. Mr. Dibner subsequently worked on housing and accessibility issues in both organizations. He left Berkeley in 1985 and continued to work for independent living organizations in Maine and New Mexico. He returned to the Bay Area in 1996. He is now the disability compliance coordinator for the city of Berkeley.

The interview was conducted at Mr. Dibner's home in San Leandro, California, on May 28 and June 6, 1998. His wife, Om Devi, was present and contributed a few remarks to the interview, drawing on her own extensive experience as a member of the disabled community and employee of CIL in Berkeley in the early 1980s. The interview was edited by the interviewer and reviewed by Mr. Dibner, who made few changes and corrections.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Kathryn Cowan
Interviewer/Editor

June 2000
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name ERIC DIBNER

Date of birth 06-16-47 Birthplace Orlando FL

Father's full name Martin Dibner

Occupation novelist Birthplace Brooklyn NY

Mother's full name Nancy Cushman Dibner

Occupation housewife Birthplace _____

Your spouse E. OmDevi Reynolds

Occupation artist Birthplace _____

Your children Noah Salzman

Where did you grow up? Florida, Maine, So. California

Present community San Leandro CA

Education High school, UC Berkeley 2 1/2 years.
Antioch College / West, Vista Coll., Self

Occupation(s) planning + design, accessibility
specialist

Areas of expertise disability rights

Other interests or activities reading, writing, nature.

Organizations in which you are active _____

INTERVIEW WITH ERIC DIBNER

I ATTENDANT WORK IN THE COWELL HOSPITAL RESIDENCE PROGRAM,
1967-1968

[Interview 1: May 28, 1998]##¹
[Berkeley, California]

Youth in Florida, Maine, and Southern California; Enrolling at
Berkeley

Cowan: This is Kathy Cowan interviewing Eric Dibner on May 28, 1998.
Eric's wife Om Devi is sitting in on the interview.

Eric, how about telling us something about your family,
your early childhood, where you grew up.

Dibner: I was born in Florida where my parents were living after the
war. The family also was involved with summer camps in Maine.
The place we lived in Maine was associated with the camp so we
had a house with uncles and aunts and cousins all living there
in the summer and we spent the winter in Florida.

After I became involved with disability issues I thought,
"Gosh! I've never been associated with people with
disabilities before." And I thought back to when I was five
years old in Florida, my next door neighbor had polio and he
was my closest friend. I didn't even think of it until I
started this reassociation. I just remember we used to play
after kindergarten or after school. I'd completely forgotten
about that until I got reinvolved.

Aside from living in Maine and being involved with camps,
my father worked as a novelist and did various jobs related to
the arts. We came to California in the mid-fifties.

¹## This symbol indicates that a tape or tape segment has begun or
ended. A guide to the tapes follows the transcript.

O. Dibner: You were starting sixth grade.

Dibner: Yes, my parents thought that the schools would be better in California so we lived in southern California. I went to Beverly Hills schools and the schools were indeed better than in Maine where I had been going to school after we moved from Florida.

O. Dibner: Your dad worked for the California Arts Council. He was the first director.

Cowan: Did you come up to Berkeley on your own or did your family move up to northern California?

Dibner: I graduated from high school in 1965 and chose UC Berkeley to attend. My family stayed in L.A. The first year I lived in the dorms in Griffiths Hall in Berkeley. I was in an architectural curriculum. I shuttled back and forth to see my parents in L.A., but after a few years my parents moved back to Maine. My folks--my dad, especially--really didn't like it in California.

Cowan: He didn't.

Dibner: He didn't. I liked it in California.

Cowan: So you lived in the dorms until you graduated?

Dibner: No. I didn't graduate. I lived in Griffiths Hall as a freshman. As a sophomore I moved out with a couple of the people I knew from the dorms. One of them was a high school friend, Richard Hersh. I moved to 2724 Channing Way and lived with Richard and two other roommates from the dorms, Joe Forster and Mike Dove, who lived there for a year--just off College Avenue so it's just a block away from the dorms.

Then the next summer I went back to L.A. and worked in the same construction work I had been doing between my freshman and sophomore years. In Los Angeles I tried to get a job working in an architectural firm and it was just--it really wasn't to my liking. It wasn't very practical, the work was tracing things and I didn't really want to be involved doing drafting as much as thinking about design.

First Jobs as an Attendant to Scott Sorenson and John Hessler

Dibner: When I came back to college in the fall of '67 I found a place on Piedmont Avenue with other friends. It was 2545 Piedmont. And as we were finding that place I was looking for work, the end of the summer of '67, and I walked into one of the dorms. It was one of the Unit Two dorms, the furthest west. There was a three-by-five card on the bulletin board there advertising opportunity to do attendant work. It had been put on the board by Scott Sorenson, I guess. So I called up and it was an advertisement to work for people with disabilities at Cowell Hospital. And that was my first knowledge or association of anything going on up there.

Cowan: So you went up there to meet with Scott?

Dibner: That's right. I placed the call, went up to see what it was about. Scott was a man who had Amyotonia Congenita which caused his physical shape to be quite different from a non-disabled person's shape. I just mention that because he was kind of different looking from what I had experienced. I guess I'd probably seen people in wheelchairs, people with other kinds of disabilities, but I hadn't had enough association--in my recollection, I had a fairly normal group of people that I grew up with, by and large, and so I guess what I'm saying is that I was kind of straight in terms of disability issues.

At that time I wouldn't say I was completely straight because I had turned on to marijuana and been involved with other new countercultural processes that were growing in society. And that was probably one of the reasons I had chosen to come to Berkeley, just to see what kinds of different things there were out there in the world.

But coming upon Scott I was--I don't want to say I was taken aback--I was dealing with something completely new to me in my experience. Scott was actually someone who had done acid a few times and was an artist and he was a little bit older than the people I knew. I don't know how old he was, he must have been around forty or something, or he wasn't that old at that time. He had on one of these psychedelic buttons that said "mutate" on it. It was this shocking green color and it had kind of an amoeba form and it said "mutate." And that just struck me as very--how can I say--it set my confusion aside, while placing me in a totally different realm of thinking. And so [laugh] although he put me at ease in his manner and

conversation, I was immediately in a different realm from what I had been in prior to that interview.

So I talked with Scott and we agreed. He said, "I do all the training. We can explain what needs to be done. See, I need to be lifted and dressed." I had never done work of that nature other than dressing myself, but I could relate to it because I knew how to dress myself. [laugh] But the catch was, it required doing it from the disabled person's perspective.

At the same time, John Hessler was in the room next door. And John was also looking for assistance, so I went and spoke with John. Actually, I started working for John a day or two before I started working for Scott because of the way things were scheduled. Scott didn't need someone for a few days and John needed someone the next day.

John was spinal cord injured and looked more like a person sitting in a wheelchair who wouldn't have a disability. In other words, dressing him and changing clothes and stuff was more like dressing myself than it would be for Scott. Scott's odd-shaped body made it a little trickier to learn, but John was easier to slide clothes on and off of and stuff, so it was probably good that I learned with him a little bit, and then I got the hang of working with Scott.

Cowan: This was the fall of 1967, you said?

Dibner: It was the summer of '67.

Cowan: Summer of 1967. So you went to work right away for them?

Dibner: Right away, yes. It was before school started and I was trying to get established in Berkeley and find a housing situation. We came up early to look for housing.

The Countercultural Scene in Berkeley: Questioning Authority

Cowan: What was Berkeley like? What do you remember about what was going on in the city and on the campus?

Dibner: It seemed a town of two kinds of atmospheres. One of them is the university and I related mostly to it as a university town. All the housing that I was familiar with was houses that

students lived in. We rented a flat and, you know, went to school.

I didn't relate at all to the community as a city. The city of Berkeley didn't mean much to me--the fact that there was a town and people who were engaged in municipal government (where I work now) or in other activities unrelated to the university. I saw the university and the thing I would describe as the other side, the countercultural aspects of the university, the anti-establishment forces, the FSM [Free Speech Movement], the people engaged in organizing on campus more or less in the face of the university.

Cowan: Were you involved in any of those countercultural events that were pretty much in full flower at that time?

Dibner: No, not really. I avoided being committed to those things. I did see them as having their virtues and I agreed with a lot of the ideas that were being fomented, or I withheld judgment, but when there was some kind of action, I would go as a spectator. I think a lot of people did that and got involved that way. I wonder how I was involved, actually, to what degree in real organized activism. But I did not think of myself as an organized activist.

I always thought of myself as more of an individual and a free thinker trying to figure out how in my own life I could redirect society, as opposed to being a part of some party or group or organization.

I was involved in the drug scene and I did feel that I was dropping out in that sense. I was listening to music. I saw that as, oh, my form of rebellion--that's the word I'm looking for--the ability to say, well, I can turn on and enjoy the fruits of the earth. It was the question authority idea: I don't need to listen to what has gone before, the establishment has no mark on me, I will do whatever feels right. So in that sense I felt kind of rebellious.

We even bought a motorcycle. My brother was living here and we bought this really junky motorcycle [laugh] which only ran about half the time. It wasn't like the Hell's Angels motorcycle, but we were being involved with the scene and hanging out on Telegraph or just trying to find where the action was. All of that brought us in contact with lots of wild and different influences. I mean, there was a group of Hell's Angels who hung out on Telegraph, so it was an interesting scene.

We used to go to concerts in the city, hitchhike a lot--I hitchhiked a tremendous amount.

Cowan: So you were more of an observer. There was so much turmoil on campus at that time with the demonstrations and all but you were more of an observer than a participant?

Dibner: Yes. I was not a rock-thrower. I don't think I did much in the way of civil disobedience, but I did engage in some marches as time went on. I didn't organize any or participate in the organizing of them but I was involved in a number of anti-war marches.

I realized how leftist some of my associations had been prior to coming here. When I was in high school, there were people organizing things that were anti-establishment. There was an underground newspaper in high school and the administration [laughs] stomped down on it. It was a real free speech issue. They tried to find out who was publishing it. It was a real example of a totalitarian administration with an underground resistance. It was very strange. And so the model was already in my mind. I wasn't writing the underground newsletter, but I mean, I was excited and interested in it.

One of the kids I played cards with in high school organized a sit-in at another school because the Board of Education in L.A. was refusing to integrate certain schools. A whole bunch of us kids went--we sat in. We had a demonstration and then we sat down in the halls of the Board of Education of the schools or something. And it was just the most natural thing to do, you know, just like the sit-in years later to get the Section 504 regs [the regulations to implement Section 504 of the Rehabilitation Act of 1973] signed.

Later on, when I started thinking about my history, I said, "Yes, well, the die was getting cast kind of all along the way; it wasn't a precipitous thing. Society was changing and people were speaking out and this was one more activity." So in the late sixties I did go to some of the marches in Oakland where there were people shot and vehicles turned over, and the blue meanies walked down the street, and stuff like that.

O. Dibner: Plus your parents--their orientation was towards civil rights, wasn't it? Your mom, especially, had become involved in some of those issues.

Dibner: Yes, my mom was involved in that. They were establishment but they were definitely very liberal, you know, my dad being

involved in the arts and my mom also coming from a journalistic family--but we were very traditional in a lot of ways.

Cowan: Berkeley felt comfortable to you, then? You were kind of already in that mode?

Dibner: Yes, yes. It was interesting. And the other thing is it's nice to be in the front and see where things are happening. I think as we talk further I'll probably say or try to express that I kind of see myself as neutral in all this, right? I mean, not being an activist, not being an advocate. I am an advocate, but in my role with people with disabilities I have thought that as an attendant, first of all, the rule is we're doing what is needed by the person who asks--we're not stepping in and saying, "I'll show you how to get dressed."

And in that regard I think I have this stand-offishness about things in general, although obviously I believe in a lot of the ways the movement--whatever movement--has progressed things in society.

Cowell Hospital Setting

Cowan: Well, when you got to Cowell who was there besides John and Scott Sorenson? How many people were residents there?

Dibner: Well, my recollection of this time--I'm not real good at where people were at certain times. It's not so much that it's a complete blur, but it's a hodge-podge of everything happening all in a period. I hope that people looking at this information won't say, "Well, this doesn't agree with what so-and-so said," because I don't feel very accurate on dates. I have tried to write down a timeline of my life in this period but it's my best guess and other people may be more accurate.

When I worked for John and Scott I believe Ed [Roberts] was at the hospital. And I think Larry Langdon came in that year. Larry may have been there previously. And I don't remember anyone else being there, initially. But fairly shortly other people started coming in. Biscamp might have been there, but I don't remember if Larry Biscamp was at Cowell Hospital.

Cowan: What was the hospital like, itself? What was the physical layout?

Dibner: Well, it's gone now, which is too bad in a way; it was kind of a landmark. It served as the student health service, on a lower floor. It was the third floor, though, where people with disabilities were housed. The floors all looked about the same: big wide halls, pale cream colors, wide doors, rooms about the size of this room--twelve by fifteen or so--with a great view. It was up by Gayley. Was it called Gayley or Piedmont?

O. Dibner: Gayley.

Dibner: Gayley. On the third floor you had a great view of the bay. So it was actually a nice location to be if you didn't have to smell the isopropyl alcohol and come through a freight sized elevator. It was a big stretcher-sized elevator, you know, with stainless steel walls so it had the look of a hospital. But the third floor was kind of abandoned, underused, and that's why it was available for use. I guess if there was an epidemic of flu or something they might have started using the third floor, but by and large there were a lot of empty rooms up there.

Cowan: You mentioned that Scott had a psychedelic button on--did they decorate their rooms? Were there colorful posters on the wall or things like that, or was it a hospital atmosphere?

Dibner: Well, Scott had some posters on the wall. It was not like a dorm where everybody puts things up all over the place. And as I recall the walls were made of a material that you couldn't get a thumbtack into. It was just very hard. I don't know what it was. But that's my recollection. I hadn't really thought about that, but I think Scott had some posters on the walls. I would doubt that John did. He might have had a picture or calendar up. The rooms were not luxurious in any way. They looked like and felt like hospital rooms.

I think Scott had his bed at a forty-five degree angle because it was most convenient for circulation. Even in a hospital room there's hardly enough room to turn a wheelchair around. His wheelchair was extended because he sat in a reclined position, so he needed room to turn around.

Cowan: Everybody had their own room?

Dibner: Everybody had their own room, correct.

Cowan: Was there a common meeting place, a dinner table? Did they eat in their own rooms?

Dibner: I believe trays were brought up from the kitchen or we went and got the trays--that was it. The trays were set on a cart in a certain location, I think. I don't remember exactly the logistics of it.

Back to your decoration question, I don't think people had--they didn't paint the rooms. I know that happened at one point later on, but my recollection is that people didn't put up any decorative trim; it was pretty staid. There may have been a common room. I think there was a common room where people could have dinner. Sometimes they would hang out and eat in one room together. I can't remember if there was a dining room. I think there would have been.

Cowan: I think Linda Perotti mentioned a big table that people gathered~at.

Dibner: Okay.

Cowan: But that may have been later, as well.

Dibner: Yes, I had this vision of a big round table someplace, real large, a real large table, but I thought that was the room that Ed moved into. Maybe there was a side wing. Ed had a larger room because of the iron lung and maybe he was right next to that kind of dining room.

Residents, Staff, and the Social Milieu at Cowell

Cowan: What about staff? Who was there in terms of nurses?

Dibner: Well, I don't remember who the first nurse was, who was in charge of things.

Cowan: Would that be Eleanor Smith?

Dibner: No, I think Edna was before Eleanor. I'm not sure. Edna Brean was definitely involved up there. I think Eleanor Smith was subsequent to her. And the other people I remember seeing were people from the Department of Rehabilitation: Karen Topp, Karen [Topp] Newsome--and who else? There wasn't much supervision, to my knowledge. There wasn't a lot of presence, but occasionally Edna would come down and say you need to do this or do that. But there wasn't any real organized presence that was obvious all the time. I couldn't even tell you where the office was.

Cowan: Did you sense that there was any, well, resistance on the part of the staff for the students to be moving towards independence?

Dibner: Well, I didn't say that. There was definitely some paternalism in the hospital. Dr. Bruyn, I believe, set the tone of laissez-faire, actually, in terms of, "Let these people develop to be the people they are going to be," but in terms of moving towards independence--of course, that concept for a person with a disability was a non-concept at that time. And the level of paternalism that I'm referring to was more because it was a hospital, because, "We are the university," we must do things certain ways. So periodically there was something that happened--maybe someone tried to decorate his room or something like that and they got told, "No. You can't put up crepe paper," or something like that.

Cowan: Some people did paint their rooms.

Dibner: Yes, well, I seem to remember hearing this but I can't remember it. There were things that--like getting in at night. I mean, this was something I've heard mentioned on other tapes; you couldn't come in after a certain hour, you had to buzz. And I don't remember whether a janitor or someone let you in, but for the attendants this was an issue, because someone needed to be put to bed at eleven, you had to get into the building. And I think they locked the elevator. We were using what used to be the emergency elevator up from the back parking lot. And I think you needed permission to come into the building. It was the same for the residents, so it wasn't like a completely free residence.

But we had the same problems at the dorms. You know, I mean, the boys lived in one dorm, the girls in another and if you came back after a certain hour, you had to get permission to get into your own residence.

So you know, it was a pretty egalitarian place up there except for the fact that people with disabilities in a hospital--[laughs]--I mean, you weren't living in a house.

Cowan: Was there a lot of socializing going on in the evening? Did people and their friends and you, the attendants--did people come in and hang out?

Dibner: As we came to know each other better. Most of the attendants were students as far as I knew and were younger people and interested in meeting other people. I don't remember the other attendants very much because, you see, usually one attendant

would be there at a time except for the fact that Hessler might have one attendant and I might be working for Sorenson and we might get to see each other and know each other that way. Also, one attendant might assist with training a new one. A new attendant would shadow an experienced attendant for a session or to learn a procedure like catheterization.

But later, when I went to France with John, I hardly knew his other attendant who also went on this trip. I mean, we'd both been working for John for a year.

There was social life, I think, just like any group of people living in a residential situation. They chat with each other and get to know each other. John came from kind of a totally different background than Scott did or than Ed did, but they were both open-minded people--I don't think they ever became real tight friends or anything. John became more friendly with Ed.

Attendant Work

Cowan: So you didn't have any prior training as an attendant, they just told you what to do?

Dibner: Well, no, I did have training as an attendant: they just told me what to do.

Cowan: That was the training. [laughs]

Dibner: Exactly.

Cowan: Did you also accompany people out onto the campus?

Dibner: Yes. Sometimes I'd go to class with them. Because I had to go to class we'd go down the hill together. I don't know that we did much socially outside. I don't think we did much socially, no.

Cowan: Was everyone in a power chair at that time, or still push chairs?

Dibner: Well, most people had both and used their power chair on campus unless it was broken. I'm not sure what kind of chair John had, but Scott had a Motorette.

##

Dibner: I think both John and Scott probably had Motorettes. Ed may have had a Motorette, also, which are manual chairs that have a motor unit on the back of them. So working with people, it didn't take long to learn what you had to do. You kind of became a mechanic because you had to dismount the motor and put it back on in order to adjust things. So quickly we learned how to adjust the cogs on these Motorettes and even got into the control boxes a little bit. Sometimes a repair person would come who would teach us a little bit about what needed to be done. And you needed to charge the batteries up every night and that was just a part of attendant work.

Cowan: What was a typical day like?

Dibner: Well, I was in school in the fall of '67 and the classes I had were mostly daytime classes, and then I had the evenings for studying or play or doing work. So I would schedule attendant work on times when I didn't have to be in class. The attendant work took two basic forms: getting someone up in the morning or putting someone down at night, which usually meant feeding them supper, or assisting with supper, and then helping with a bath or with undressing and getting into bed or doing other kinds of personal care.

So for me a day often would consist of doing an hour-and-a-half or more of work in the morning, going to some classes, going home and hanging out, and then coming back in the evening, sometimes nine, ten o'clock at night to do a couple of hours of attendant work.

Cowan: How were you paid?

Dibner: In cash or a check. I don't remember at that time how attendant services were financed but maybe I was paid through some aspect of the hospital, through Rehab or something. I don't remember how we kept track of the hours or what the payment mechanism was.

Cowan: Was it an okay amount?

Dibner: It was pretty minimum wage, I think. I was going to say two dollars an hour but it must have been more than that, although it could have been two dollars an hour at that time. I think it may have been.

Cowan: What did you notice on campus? This was the first time severely disabled students had been on campus. Was there acceptance? Did you notice any surprise?

Dibner: Well, yes. Some of the buildings were inaccessible so there was some mention of problems at times where a class was inaccessible to someone or there needed to be some change in order for the person to take the course--but by and large I didn't hear too much about that. No, these guys were going to school. We didn't have any mutual classes, so I don't really know what happened in their classes.

Cowan: I've read in other interviews that Zona Roberts, Ed's mother, was quite active. Was she participating in the program when you were there, or did that come later?

Dibner: Well, it wasn't a program as far as I knew. Yes, there were individuals who were getting financed through Voc Rehab [Vocational Rehabilitation], I think. I may have met Zona up at Cowell but I don't remember her at that time--although, as I say, my memory fails. But I wasn't working for Ed. I did fill in for him once or twice, but by and large I didn't work for Ed.

Cowan: Who did you work for?

Dibner: Just for Scott and for John. And I did some work for other people who were there. I would fill in. I think I might have worked a week for Biscamp or a week for Larry Langdon. I did work for Larry Langdon for a period. Jim Donald was there, but I didn't work for him on a regular basis, but my brother did at some point. I had forgotten that. My brother lived with us on Piedmont for a while and worked for Jim for a few months.

You know, this wasn't a very long period. I lived on Piedmont from the late summer of '67, and I started a relationship with Vicki Jardines, who moved in with us at the beginning of 1968. And by the summer of '68 I had gone off with John Hessler and Vicki and Geof and Steph to France. So it was less than a year from when I first started attendant work to when I went to do what was really live-in work--traveling and live-in with John Hessler. It seems like just Scott and John that I was working for in my recollection, but I probably did some work for others, yes.

The Rolling Quads: Disability Identity and Activism

Cowan: Had the Rolling Quads formed up at that point? Was that while you were still there, or did that come later?

- Dibner: I think they may have started fomenting that group around in that year. I think they kind of--there was a kind of a clubbiness that developed amongst people who were up there. I don't remember when Jim Donald and Larry Langdon and Biscamp came there but it must have all been in that year because I really didn't work there much after I came back from France. So there must have been five or six people there in that, in 1968, when Hessler went to France.
- Cowan: He went to France before it was the Rolling Quads?
- Dibner: I can't--I don't know the sequence. As I was saying, I tried to stay aloof of that. "Oh, you guys want to organize and have your own movement? Go ahead, have your own movement." I think the Rolling Quads started forming in--it must have been in the beginning of '68. Do you know, Om Devi?
- O. Dibner: I don't know the dates on that. I know that Larry Biscamp was involved in that, getting it going, agitating it.
- Dibner: I don't know how much agitation there was. I think it might have just been what they called themselves beginning up there at Cowell. They just gave themselves you know the name, like the Crip Group, right? So they called themselves the Rolling Quads. I remember thinking about that term, though, that I was taken aback at that time by people self-identifying with their disability. As a person with a disability, why do you want to identify as a person with a disability? You want to deny that part of you, is kind of what I was saying in my mind.
- Cowan: Back then?
- Dibner: Yes, right, in 1968.
- Cowan: So that was a new idea for you?
- Dibner: Yes, and it was the same thing when Susan Sygall came to CIL and said, "We're going to do recreation." I said, "Come on, come on, people with disabilities don't do recreation." I mean, Mr. Liberal here didn't get it, right? The idea that you would self-identify in a sense and then brag about it, well--I was saying, "Hey, I don't want to associate with that group. You know, if you want to go and do your thing, go do your thing." So [laughs] it's an interesting philosophy.
- Cowan: It is. But you did notice that they were forming up as a group? Did you have a sense that this was going to lead to something?

- Dibner: No, I thought it was more of a clubbiness than anything conspiratorial. I didn't realize that there was activism in it. To me, it was a kind of a party, you know: "This is what we call our party." There were ongoing things at the hospital that I must say I don't--I don't remember when this group actually took a name and started being a group, or whether it was four or five people up there just hanging out together.
- O. Dibner: Biscamp liked to create things. He liked to get things going and I can just see that as they hung out they started saying, "Look, we want to make some changes."
- Cowan: Did you notice that people were beginning to ask about changes or think about them or talk about them?
- Dibner: Well, yes. There were one or two crises in that year where there had been a threat to either yank the rug from the program or to keep the people in the program from doing certain things. I think one of the things revolved around being able to get a key to the building.
- Cowan: Really?
- Dibner: There was some issue about access to the building. I don't really remember what the other ones were, but there was kind of elbow-swinging to try to get more space and breathing room and ability to do things. I don't remember the specific issues, though. I just wanted to be an attendant, you know. [laughs]
- Cowan: Yes. [laughs]
- Dibner: Yes, I'm just doing my job. I just work here.
- Cowan: [laughs] But that led eventually to the Physically Disabled Students' Program [PDSP] developing, did it not?
- Dibner: I don't know. I really don't. Maybe so. You know, I really didn't think I immersed myself in it. And in the same way I worked with the Disabled Students' Program. I saw it as just a job. Luckily, I had some skills that I'd learned from working with people with disabilities--or some experience; it turned into skills. So you can say that I'm pushing the movement, helping the movement or whatever by working there, by doing this, but I never saw it that way. I didn't see that this was happening around me as a movement. It was just things people were doing on their own.

Cowan: Well, people began moving out, though, didn't they? Did Scott move out, or Larry, or did people move out into the community to live independently?

Dibner: Scott had discussed that when I worked for him in '67 and '68. While I was there I don't really remember anyone doing it. One thing that I remember is Scott's discussion of his life before he got these opportunities to participate with the university. He had been in nursing homes. That's where he had lived. His parents had been kind of cruel and abandoned him to the nursing home system and so he had been in some kinds of institutionalized settings that were a far cry from the space at Cowell. It was really wonderful to him, he said, to be able to go to school and stuff. But he did not ever want to go back to those kinds of places.

Ten Months in France with John Hessler

Dibner: John Hessler also had been in a county hospital after his accident which hadn't been that many years before he came to UC. John's experience also was that they weren't great places to be in, county hospitals or nursing homes, so there was a sense of not wanting to go back. People wanted to go forward. They had been given the inch--

Cowan: And they took it.

Dibner: And they appreciated it. So Hessler asked if we wanted to go to France, Vicki and I. And [pause] we agreed to accompany him to France. He somehow had convinced Voc Rehab that as a French major he needed a year in France. He was going to attend the Sorbonne, and enrolled in it, or did whatever--I don't know whether he actually enrolled; he did preparatory entry exams or something, and somehow arranged the flight for all of us. Geof Wells was John's other primary attendant. He had also worked for Ed. Geof and his wife Steph went ahead and rented a place outside of Paris. So John actually did move out. He never went back to live at Cowell--maybe he did briefly when he came back the next year.

For that year, or almost a year in France we were traveling around and we were living in a villa outside of Paris. I wouldn't say it was normal life at all. It was quite a weird experience. It was a time when Paris was shut down for a week, also, because of student riots there.

When we went with John on that trip, I didn't know if I was ever coming back. I severed all my mental ties because the draft was happening. We didn't know what our numbers were going to be in the draft lottery and I thought I probably was not coming back.

Cowan: You said you lived there a whole year?

Dibner: It was ten months, something like that. I think it was ten months. I don't remember exactly. Zona Roberts came and visited there near the end of our stay.

Cowan: Did John go to school?

Dibner: John went to enroll at the Sorbonne and it was totally inaccessible. It was made out of these giant old stones and you could not get into the place. He came back and he said, "I'm not going to the Sorbonne." He studied at home, and he actually did: he did lots of study, he read, and I think being immersed in the French environment was probably the biggest aspect of value in the learning experience, there in France. And of course, as you know, he went on to be a great French scholar--not! [laughs] He went on to be a good administrator and work in government bureaucracy. But he learned how to use the government to get what he needed.

II THE BERKELEY SCENE AND THE PHYSICALLY DISABLED STUDENTS'
PROGRAM [PDSP]: DEVELOPING THE INDEPENDENT LIVING MODEL, 1969-
1972

Attendant for Scott Sorenson Again: Rent Strike, Scott's Death

Cowan: So you all came back to Berkeley.

Dibner: No, not exactly. Vicki and I had a falling out and--well, I need to backtrack a little bit.

While doing all this, around the end of '67 the beginning of '68, I started doing real poorly in school. I wasn't paying attention to it. There were so many things going on around me, the career track was kind of faded. There was no concept at all of being able to go out in the world and be successful. That "straight" world was a non-choice at that point. I had enough trouble with school that I was on probation. I wasn't able to bring my grades up and in March of '68 I dropped out. They told me I'd have to fill out a form in order to withdraw. And I said, [laughs] "No, I don't have to fill out any form. That was the whole problem!" So I didn't. So I never finished UC.

So we went to France for almost a year. In the spring or summer of 1969, coming back to Berkeley wasn't something I did directly. I didn't have a lot of attachment. I didn't know what I was going to do. I was drifting. Vicki and I split up in France. I went and stayed with my folks in Maine for a while, then took several months traveling cross-country with two guys I'd met on the boat coming back from Europe, Angus and Tim.

I didn't have a place when I came back to Berkeley; we were just staying at people's places. I got in touch with Scott after a while and learned that he had moved out and was living in an apartment on Dwight Way--2430 Dwight. I moved in

with him. I started doing attendant work and moved in with him.

So John was back in Berkeley. He picked up with the Disabled Students' Program activity and he became director, I think, right away. Yes. John was working at the Disabled Students' Program. I was still hanging out, but I lived at Scott's apartment. There was a guy there named Paul Dresher. Paul is a musician now of some renown, I guess, but he was there for a little while. We overlapped and then Paul moved out and I was Scott's live-in.

Cowan: Paul was his attendant?

Dibner: Yes, Paul was his attendant, also. I did attendant work--I did the live-in work. Scott had some other people who assisted him. But I can't remember if Scott was in school--I think Scott had dropped out too. Remember this was the "Tune in--turn on--"

Cowan: Tune in and drop out.

Dibner: Tune out and drop off. [laughter] There was a lot going on at this time.

Cowan: Was this now 1970?

Dibner: This is the fall of '69. When I started staying with Scott it was October of '69 so there's a period of the summer when I was going from Maine across the country. Then sometime in the late fall of '69 I started living with Scott.

Cowan: So when you got back here--PDSP was organized and going and John was already working for it?

Dibner: That's correct, I believe so.

Cowan: And you moved in with Scott.

Dibner: That's correct.

Cowan: How long did you live with Scott?

Dibner: Well, you know, what we described up to this point was a season at Cal, a season in France, it was two years of time, I guess, we've talked about.

My experience with Scott in that period [1969-1970] was a much different experience from what had happened before. I

only lived with him for six months or something but we'd gotten to know each other. And I think--what do you call it? It's not personality type--sensitivity. We had much closer sensitivity than John's and mine. John was more intellectual. Scott, he was an artist. Scott was an older man, he had a moustache--John eventually grew a moustache, it was kind of a trait for John--but Scott was kind of a beatnik. He had dropped out of school--it was a time when there was a lot of tension about the war and about society in general.

We got involved with the rent strike that was going on in Berkeley. There was a generalized rent strike around Berkeley and someone came around to our apartment--it was one of these big tacky-tacky apartments--seventy-five apartments in the building--and someone came around and organized us. We participated in the non-payment of rent to fight the landlord (pigs). The whole building was on rent strike for a good number of months. Units were getting broken into by vandals and there were--I remember one day there was this box of dog crap in the lobby someone just set there. There were all these kinds of incidents of deterioration of society going on around. [laughs]

Scott at the same time had dropped out of school because he wanted to be an artist. Rehab did not want him to be an artist, it wasn't a viable alternative. He didn't know what he was going to do. He told me he would rather die than go back to live in a nursing home. So I'm hanging out in the apartment, just doing his attendant work, you know, being a little bit chummy but not really cognizant of what was going on around me. I was just doing what needed to be done, I thought, and trying to engage in some of this anti-establishment activity, and just kind of hanging out. Later on I built this house on the back of a truck and my whole idea was really dropping out. But I was working for Scott because it was a place to stay. We take the convenient bed.

Scott, however, had deteriorated in health. He was depressed about not having a career opportunity. He was inventing certain things. He invented this kind of speaker system that had a special kind of cabinet that would resonate a certain way and he was into the electronics of it. We were trying to build some electronic stuff and I had no idea of how to do this sort of thing. He was trying to invent things that he could do to survive. And there weren't any opportunities, there were just no options.

Scott died in March of 1970--around there. He had had pneumonia. He had improved and several months or a month or so

went by and his doctor came in--because Scott just wasn't feeling well--and the doctor said, "Well, I don't see any problem." And the next day Scott was dead. This was a result of the pneumonia that the doctor just couldn't see.

I don't know if Scott could even get Medi-Cal--he must have had. Yes, he had Medi-Cal, that's how he was getting the doctor's services, but the in-home support was barely adequate I think. I don't know how he was paying me; I don't know if in-home support services had been established at that time. But he had barely enough money to survive. I mean, if there hadn't been a rent strike I don't know how we would have been paying rent. And the Disabled Students' Program was for UC Students. He wasn't a UC student so there was really no place to go and nothing to do in terms of saving himself. And of course, his kind of disability is something that doesn't allow you to live very long. He might have been in his forties, I don't know. He had lived to his life expectancy, but it was a very disappointing kind of event, so to speak.

##

Dibner: Scott dying was probably the first time I've seen someone dead, I think. And it was very sad. I was kind of shocked by not having known what was going on. I felt guilt and I felt helpless at the same time.

The medics came and the doctor came and said, "Whoops, well, I guess we hadn't diagnosed that right." And they took him away--his body away--within a few hours, so it was immediately like nothing happened, sort of. [wry laugh] So there I am with this apartment and I didn't know what to do next! I guess this is one of the results of floating without planning, right? [laugh]

I went and found Scott's parents who lived out in--what's that resort out in Concord [California]. Rossmoor Leisure World. Actually I had gone there once. He had told me he never wanted to see them, they had abandoned him, but I went and talked with them. And whoa, it was like talking to someone from the Stone Age. It was really an experience. They didn't want to come to a memorial service or anything.

There was a memorial service. I don't remember who put it on. I think Newman Hall did a service for Scott. Scott had a little bit of religion and he would go to Newman for counseling and spiritual support.

He also painted. I have his paintings. There were about a dozen of them that he left. But he didn't have any family at that point except, if you will, me. His parents were not his family.

Outside the Mainstream

Cowan: So you were left kind of on your own. Had you finished building your house on your truck?

Dibner: No, I hadn't started, yet. Except I had this idea. After traveling across the country with Angus and Tim I'd thought about the idea of just being a rover. I was definitely interested in trying to start a way of life that was separate from the mainstream of life and allowed me mobility and access to things.

Another thing that happened at this point, although I wasn't clear about it, was that I learned a lot about housing issues from the Berkeley Tenants Union and from just watching things around me and rents going up to ridiculous levels that no one could afford. And I learned a lot about access issues and about the difficulties of independence without appropriate support services. Scott had talked about this a lot, that there just wasn't a service program available that could meet all those needs. And obviously this fits in a lot with what I've done since then.

I found a place in Oakland--468 58th Street--where I knew people and started hanging out with those people.

Accessible Housing, Curb Ramps, Assistive Technology

Cowan: Well, did you get a job then or were you just hanging out?

Dibner: I think I worked for several months at PDSP to make some money.

Cowan: Right then, just after Scott died?

Dibner: It was the fall of 1970, so it wasn't right after Scott died. I don't know what I did for that summer, to tell you the truth. I probably went back East and visited with my parents for a

while and came back. I did go back and forth to Maine to visit every once in a while.

So sometime in the fall of 1970 I worked for several months at the Disabled Students' Program. Zona asked me--I did know her at this point. She called up and said, "Would you like to be a housing counselor?" So I went to the Disabled Students' Program and was a housing counselor that fall.

Cowan: They hired you as a housing counselor?

Dibner: Correct.

Cowan: I read that there was a housing survey for trying to find accessible apartments for disabled people as they were moving out. Do you recall doing one?

Dibner: I recall that there was one. I don't remember if I did it. I may have. If I was at the Disabled Students' Program it would be logical, but it probably consisted of just walking around and looking at the big apartment buildings that might be useful to live in. There was a card file of housing, I seem to remember.

Cowan: That was for accessible buildings?

Dibner: Yes, but I don't remember much of the survey. Maybe someone did a survey. I think maybe Ruth did some of this, Ruth Grimes.

Cowan: What would make a building accessible? If you had done something like that, would it just be looking if they could get in the door? Was there some requirement for the room size, or the bathrooms, or anything like that?

Dibner: There certainly weren't any standards at that time. In '70 there were some guidelines out there but they weren't particularly designed for housing and I certainly wasn't familiar with them. What you would ask for in terms of accessibility would be a lot different from what you'd ask for today, but you'd need to be able to get to each floor, or the floors you need to get to, to the front door of your unit and get through the door. That would be a great advantage right there.

And the same is true today. If you can't get in the front door, it doesn't work. When I looked for this house, for instance, when Om Devi and I moved here a couple of years ago,

we had to find a place that was close enough to the ground it could be ramped.

Hessler lived on a place on Haste Street right around the corner from where I work now which was a cottage behind a large older apartment building. It had one step at the door and one step at the porch and so I built a little wooden ramp for him to get up to the porch and then to get up into the apartment. I guess maybe we had done that in France, I'm trying to remember. I think maybe we had to build a little ramp in France, so that was one of my first experiences with ramps, right, and learning that if you're closer to the ground, you don't have to build so much of a ramp, like, duh! [laughs]

Cowan: I certainly have heard your name associated with ramps over and over again, Eric. There is this story that you were building curb cuts and ramps in Berkeley sort of unofficially. Is there a story behind that?

Dibner: Well, you didn't hear about the nitroglycerin where we were blowing up curbs and [laughter] and jackhammers in the middle of the night, where we'd go and we'd jackhammer up all these intersections and then the city would have to fix them.

Cowan: No, I didn't hear that story. Is that a true story? [laughs]

Dibner: No, neither of those are true stories, actually. [laughs] That was a little later when Ed asked for some ramps to be-- there were some corners where he had problems going from his house to CIL, or maybe it was the Disabled Students' Program. So I got a bag of cement and went out. They were real low curbs, like a couple of inches, at Dana and Dwight, probably at Ellsworth and Dwight, and I think I did one at Ellsworth and Blake. It was just to bevel the corner. I mean, we didn't build curb ramps, we just put some cement down to make it useable.

O. Dibner: They were the first ramps.

Dibner: There were curb ramps in other places at that time.

O. Dibner: Oh, were there?

Dibner: Yes.

Cowan: I did read that the city rebuilt--this was in Hale's [Zukas] interview--that the city rebuilt Telegraph Avenue and did ramps.

Dibner: Yes. I don't remember how--I think they just decided to do it. Hale and I have discussed this in the last couple years because now that I work on curb ramps in Berkeley, I'm interested in when they started. There was a plaque put in last year about the first curb ramp, which wasn't down on Shattuck where the plaque was put, but was up on Telegraph. I think the city in '68-'69 had this project to rebuild the sidewalks on Telegraph. They put in all that pebbly aggregate sidewalk stuff and somehow decided to put ramps in. And Hale might have been involved in helping them to figure out where to locate them.

O. Dibner: They must have been encouraged by the people to do it. People raising their consciousness about it. The city of Berkeley doesn't just do stuff like that. Or didn't.

Dibner: That project happened while John and I were in France. When we came back, Telegraph was all accessible. I think that that--whether it was an accident or as Om Devi says there was some activism around it--the fact that Telegraph became accessible was a very important key foot in the door, so to speak, because it gave an avenue you could travel, you could move about, you could go to the cafe, you could go to the bookstore, you could go to school, you could go to the whole residential neighborhood south of Dwight Way [without needing assistance at each curb].

A lot of Berkeley has flat corners, not on the bigger streets as much as in the residential neighborhoods. Lots of south campus area has intersections where the street comes up to the actual curb. And as I said, some of them don't quite meet and that's why Ed needed one or two inches fixed.

This was a design that happened earlier in the century and it wasn't for access as much as it was for pedestrians to not have to step down at the corner. The water goes underneath the corner in a cross culvert, and that allows the intersection to stay kind of flat. I think that feature also was something of a catalyst in making it possible to live in this area.

In the seventies, also, there were a lot of tacky-tacky apartment buildings built with elevators. And even though the elevators might be kind of tiny and there's other problems with the buildings, they're flat. Some of them have steps and some of them don't have steps, but generally you roll in and you can get in to the elevator. It was a massive availability of housing. The bathrooms might not be accessible but at that time people I worked with were using commodes, just not going into the bathroom.

Cowan: Do you recall, in terms of living independently, any kinds of gadgets or things people put together to make it easier?

Dibner: Yes, these were memorialized in a booklet that Susan [O'Hara] provoked be put together which showed a bunch of assistive technology--primitive assistive technology, or what we would call low-tech, these days--in use. Mary Ann Hiserman and John Hessler are in that booklet. There's a product called pip which is a rubber lever handle on a door, so that's one kind of thing. Another is one is a string on the doorknob so you can pull the door closed behind you without backing your wheelchair against it. Other things are extension handles on keys and extensions on the turn latch on a lock--you can just tape a stick on it.

Let's see--Scott had a long reacher stick. He had a dowel, Scott used a dowel to reach things. I think he also had one of those reachers that you squeeze and it grips. So some of these things were available in the medical industry already. But some of them were just adaptations that people made.

The concept in adaptive devices and the assistive technology really is reach and ramp to me. A ramp is a bevel between two elevations. You're trying to get from point A to point B. And reach is bringing the object closer to you by extending it or changing its shape somehow so it's more manipulable. These are principals that carry through in the accessibility standards today.

In order to reach something you need location--you might have to move it closer--and ease of operation--it has to turn easily. So you extend it to make it a lever, which gives you greater force and also brings it down closer to you.

To me, the ramp is really symbolic, in a way, of how I see proceeding through the system. You're trying to get from point A to point B and you need to figure out how to lever your way--a ramp is a lever--and you need to figure out how to move objects that are blocking your path. So I use that analogy a lot in looking at how we're trying to do things. People aren't really trying to make a different world; they're just trying to build ramps.

PDSP, House on a Truck, and the Roberts' Green House

- Cowan: I think that's a good way to put it. So--just to think where we are--you're working at PDSP and getting interested in the housing issues?
- Dibner: Yes.
- Cowan: Was it just because it was part of your job?
- Dibner: Well, it was because I had some of this experience of finding housing. I had looked for housing for myself, I was familiar with the market, a little bit, I was into architectural issues, and I'd been a live-in attendant. There were very few people who had been a live-in attendant at least in the realm that we knew of. So--and you've got to remember how ironic it was to me to work for the university because I had rejected the university! In a way I saw it as, "Oh, I can get some money out of this situation, right?" [laugh] So I was kind of gloating that I could do that.

But it was what was needed. Zona and whoever else--John, I guess--were creating the Disabled Students' Program to figure out what people need. Part of it was counseling, we saw that people needed counseling. But as it turned out, it was more issues of practical living. Part one was what do you need to get through daily life: practical issues. And the other was counseling in the terms of peer counseling: here are people who have the experience, who are your peers, who have the same--they may not have the same disability, but they face some of the same challenges and know ways to deal with them. Some of them are psychological challenges, some are actual tricks of the trade--learning how to get someone to pay for your college education or something like that.

- Cowan: Did you work with Hale at all in an official capacity?
- Dibner: I don't know when I met Hale. I think I must have met Hale at some Disabled Students' Program activity--there were parties at the Disabled Students' Program. Herb Willsmore was also involved in this group--Willsmore was up at Cowell in that first year.

I'm trying to remember, I seem to think that I worked at Cowell a lot longer. I can't remember when people started coming there. I must have been doing attendant work most of this time after I got back into the scene at the Disabled Students' Program. I probably did some attendant work.

Cowan: At the same time?

Dibner: I think so, yes. Hale, as I recall, had not been involved in the Cowell program at all, but was attending the college as an independent citizen living in Berkeley. He lived at his mom's house.

I developed this idea I wanted to build a truck. I had worked at the Disabled Students' Program for a few months in 1970, and I quit that and went just to do my truck thing. I went with some friends up to the Napa Valley, found an old farm truck and hauled it back and fixed it up. It took me several years and I never did finish it and eventually sold it. The idea, then, at the beginning of '71 was to do as little participation in regular career type stuff as possible, but I did keep going back and working.

I worked in three separate periods at the Disabled Students' Program. I did some attendant work. Later, I did some work for Hale. I actually lived with him.

Cowan: What gave you the idea of building a house on your truck?

Dibner: Well, for one thing I'd read a Frank Lloyd Wright book where he discussed our future civilization and one mode of living he thought was mobile home living. I didn't want to live in a Winnebago, so I had this vision of what I might be able to do.

The truck was funky. It was a '36 Ford, two-and-a-half ton flatbed, and it was solid, it was real stuff, you know. [knocks] It was built out of solid metal. You hit it, it didn't sound tinny at all. And I put an engine in it. I was hanging out at this house in Oakland where I did most of it. In the fall of '70 and the beginning of '71 I was living at this house in Oakland, staying in the truck or staying in the house.

Cowan: You could live in the truck while you were building it?

Dibner: Once I got the walls up. It took me about a month to actually get the structure built and then I moved into the truck, which was parked right out in front.

Cowan: Did you have that truck parked near the Roberts' house at some point?

Dibner: Later on, yes. I got the truck running and I would go places. But the idea was to park the truck, not to drive the truck.

[laughter] I got hassled a lot. I got arrested several times, mostly by Oakland cops. It was always Oakland cops.

O. Dibner: Can I interject something?

Dibner: Go ahead.

O. Dibner: I moved to California, to Berkeley, in 1972, and I saw that truck a lot over the years. [laughs] I saw that truck around. I was very intrigued by that truck.

Cowan: I'm sure I saw that truck, too.

Dibner: I can show you pictures of it.

I started working again at the Disabled Students' Program, and I realized that you can't just live in a truck and survive. You do need some money and so I worked for something over a year at the Disabled Students' Program--from July or thereabouts in 1971. So the end of '71 and into '72 I was working at the Disabled Students' Program.

I started hanging out at the green house--2223 Ward. I got very close with Zona and Ed, Randy, and other people in that house. Linda Perotti lived across the street. Walter [Gorman] lived in the house and Carter [C. C.] Collins.

Cowan: You have a good memory for these names.

Dibner: I was parked outside of their house for a year, or something like that. It seemed like quite a long time. Walter and I and Om Devi and Walter's partner are all still very close friends--and Zona. The green house was a very good place to feel things changing and see what was happening in that time, I guess--the fall of '71.

Cowan: While you were at PDSP, though, do you have any thoughts on what John was like as a director? Were you there on a daily basis?

Dibner: I was there. I don't know if I was working full time. I don't think I was working full time. I think it was maybe three days a week or something.

I didn't know how John was as a director. He and I had a very good relationship in terms of understanding each other and not having friction at all. I think he was a quite able administrator. I always thought he was kind of conservative and not very forward thinking but, in fact, that was not the

case. He could formulate a practical way of dealing with which way the program needed to go. I think between him and Zona-- Zona's much more visionary. I guess Zona could be an administrator, but she's much more right side of the brain, and I think John is more left side of the brain.

Cowan: So he was able to get this program going. Was it at Cowell to begin with when you were there?

Dibner: I don't think it was ever at Cowell.

Cowan: Oh, it wasn't?

Dibner: No. It was off campus, initially. I don't know if it ever had any time at Cowell at all. When John came back--remember I wasn't in Berkeley, I didn't come back for a while--John immediately went into working with the Disabled Students' Program. I remember there was some discussion of "What's he doing, man, he doesn't know anything about running a program. And not only that but he's disabled." [laughs] As it turned out it was a very wise choice and he knew his stuff.

Cowan: Was it on Durant?

Dibner: Yes, it was 2532 Durant, something like that. It was behind Top Dog. I think that was its first office.

Cowan: It was never in John's apartment that you know of?

Dibner: It's hard for me to really say because I wasn't here.

Cowan: I heard a lot about the ramp behind Top Dog to go up to that office, that it was a pretty steep and scary ramp. [laughs]

Dibner: Yes, well it was a one-to-six slope and it was about forty feet long, I think--fifty feet long. And when you came down to the bottom of it, you were right at a driveway that was blind, so cars would have an opportunity to squish you if you happened to get there at the right time. But it never did happen. I think we put up a mirror at some point. But that was the longest ramp you could get in that would get from the bottom to the top. And it was quite a job to build it that way. They got that place, I guess, because the rent was reasonable and it was close to campus.

Hanging Out in Berkeley: The Food Conspiracy and Other
Alternative Directions

[Interview 2: June 3, 1998] ##

Cowan: Eric, when we stopped in our last session, you were just talking about living in your truck, parking it at the green house. Do you care to carry on with your recollections of the green house and who lived there?

Dibner: Yes, I'm not sure where we left off. It was Zona and Ed's house. Zona had a number of people living in the house with her. Ed's brother Randy was also living there. Ron Roberts was there sometimes.

The truck was a plan on my part to move out of the system in a way where I could live independently and have mobility and go where I wanted. But it wasn't a very fast process of building or of moving.

I had worked on the truck at the house at 468 58th Street in Oakland when I was hanging out with those people--who I don't think I mentioned. It was John Jaehing, Burt--who was a draft dodger--and a guy named Ed, who all lived in that house. And Dennis Waring who's an artist lived around the corner with David Janss. Eddie Money, who was Eddie Mahoney at the time, was also in and out of there. So we all kind of hung out and partied for a year or so.

I was involved with the Food Conspiracy which was in that neighborhood. My only real activism at the time was being involved with this community effort.

I did some work trying to clean up the neighborhood but there wasn't a lot going on. So although I was almost completely dropped out at this time, I wanted to reconnect in some ways.

I also abstained from relationships, if you will. I didn't want to get involved with anything.

Cowan: The Food Conspiracy was--

Dibner: The Food Conspiracy was one of the buying groups that were in the area at the time. There was a movement at the time for people to form these buying clubs where once a week one of the members or several of the members would go down to the market in downtown Oakland at four a.m. and buy a large amount of

produce and bring it back to a location in the neighborhood--it was a very grassroots organization--and provide cheap produce or at-cost produce for its members.

So I got involved with that. We wrote a booklet on how to form your own co-op Food Conspiracy. I can't remember what ours was called--it was called something like North Oakland Food Conspiracy or something like that. And there were several dozen of them in the East Bay. They were all around. And I guess there still are some that have kind of evolved more into farmers market efforts now.

Cowan: Food banks, perhaps.

Dibner: Food banks, maybe, yes. I'm trying to get to the green house, but I was giving you my frame of mind.

I didn't have a lot of income at the time. Although I was doing some things that I made a little money at, I didn't do a lot. I may have built a ramp or two.

I did have association with Zona and Ed. I just don't know how I even first went over to the green house. Ed was at the Woodside--what was the school he went to over there? It was an alternative school where he was doing some graduate work, I guess. Common College is what it was called. He and his brother Mark were both involved in it at the time. I went over and visited him, I drove across the San Mateo Bridge in my truck and visited him in Woodside and spent a number of days there and got a little friendlier I guess. And so later on when he moved back to the green house after he was done at Common College, I felt more a part of the scene there.

Cowan: Were you still doing any work as an attendant at this time?

Dibner: The summer of '70 I didn't do attendant work that I can remember. But in the fall of 1970 Zona asked if I would be interested in working as a housing counselor because I'd had some experience in housing situations which right now seems, well, gee, that's fairly limited experience. I'd lived with two people--Scott Sorenson and John Hessler--and done some attendant work. But for that time, there weren't a lot of people around doing it so I was as likely a subject as someone else. And I did know about building things and about how to find housing, so I worked as a housing counselor at the Disabled Students' Program.

It was a several-month job and it was just kind of a way for me to make some money. And when I felt satisfied that I

could go on for a number of months after that, I again quit that job, sometime the end of '70 or the beginning of '71.

During the winter of '71 I was living in my truck full time. I wasn't paying rent any place. I was studying a number of alternative directions. I looked into anarchy: what does anarchy mean as a political movement, and the history of social change, and there was this effort some people had called de-schooling which was about unlearning ways that we had been taught. I was really into talking about it. [laughter] I was making a study of it. Actually, later on at CIL this was something I tried to document when we were going to Antioch College West.

A Little Bit of Everything at PDSP, 1971-1972

Dibner: In the summer of '71 the Disabled Students' Program again beckoned, if you will. I worked from the summer of '71 to the fall of '72 at the Disabled Students' Program. Which was maybe fourteen months or something like that.

And although I was a housing counselor I was learning to do all kinds of things. I worked on whatever was needed. And as Om Devi pointed out, I was full time for a while there. It probably changed; it probably went from 80 percent to 100 percent back to 50 percent just depending on budget issues. I was being very flexible and I did the weekend stint which was two days on the weekends full time, staffing the office by myself. So I was the emergency on-call person and worked on chairs that needed to be worked on during that time and did other staffing duties.

Cowan: Would that be what mostly on-call was about--wheelchair repair? What other things?

Dibner: I probably did attendant work, too--emergency attendant work, yes. And I probably helped with looking for housing.

Looking for housing is an extremely time-consuming prospect. There is a limited amount of housing available and there are very few of those that are available which might be accessible to a person who has a disability. So for someone to find an apartment or a unit when they're moving to Berkeley was extremely difficult. And just driving two or three people, or driving around to two or three apartments could take a whole day.

- Cowan: Did you create a card file or a list of houses, or did you have something to work from?
- Dibner: Yes, I think we had some rudimentary data base. [laughs]
- Cowan: Sheet of paper? [laughs]
- Dibner: No, I think there was a card file of apartments that were available or commonly had units turn over--the larger apartment buildings.

Campus Committee for Removal of Architectural Barriers

- Dibner: Another thing I was involved in--maybe not right in the beginning, but I got involved with the Campus Committee for Removal of Architectural Barriers. I'm not sure when that started, but I stayed with that group for a long number of years--even when I was starting to work at the Center for Independent Living.

The Committee for the Removal of Architectural Barriers was one of the first real organizations I joined to be active in, you know, aside from the Food Conspiracy effort. It was something that was working with the bureaucracy, in the system, trying to change the system through an organized committee.

- Cowan: Who else was on the committee?
- Dibner: Well, Mary Ann Hiserman was on the committee. I don't know if Michael Mankin was on it. I think Dorothy Walker was the staff person. And Ray Lifchez probably worked with it somewhat, but he came along later. So in the beginning, I'm hard pressed. I've probably got all the notes from the meetings in those boxes in the garage. [laughs]
- Cowan: Were university people there?
- Dibner: Yes, well, Dorothy Walker was from the university, yes.

It's interesting you asked that question, because I was working for the university but the dichotomy is that the Disabled Students' Program, although an arm of the university, was a small fairly independent body within the university, more like a--what's the term--like a flea on their back and/or something that wheedled its way in and was trying to grow. So it did have something of the antagonist to it.

Cowan: Did it?

Dibner: Yes, it was not something that the university had adopted out of their own thought process. It was something, as you know, that had grown out of the Cowell process.

Cowan: Do you recall any instances of resistance from the university in refusing to allow some aspect of the program to develop or anything like that?

Dibner: I know there was a constant struggle around things like that. I can't give you the specifics. Zona really knows some of that process better. I don't really recall that, specifically.

Cowan: But you had an overall feeling?

Dibner: Yes, there was definitely the effort to try to overcome bureaucratic resistance.

Part of that was in the CRAB committee--that's why the CRAB Committee formed, because many of the buildings were inaccessible. Much of the campus had not just hills but steps, and doors that couldn't be opened, and classrooms that were on mezzanines, and classrooms that were tiered. The lecture halls didn't have any place that you could sit with a wheelchair very comfortably. And just trying to get classes moved was an effort. So the idea of CRAB was to make the campus accessible and remove barriers.

We eventually got the campus to adopt a plan to identify barriers and work on their removal. It was kind of a piecemeal process that grew as time went on.

Cowan: Did you know this was your interest? Did you say, "This is something I'm really interested in," or was it just another thing that needed to be done and you did it?

Dibner: I think the latter. I don't know how conscious I was of it fitting into the growth process of Eric Dibner or the movement.

It was a rough spot in the work that we needed to do, so we needed to smooth this process with the university to make things accessible. As far as I know there weren't other committees like this around. And to me it was fitting to work on this effort because I was architecturally inclined. I hadn't finished architectural school but it gave legitimacy to my rudimentary architectural skills, as well as used the knowledge I had as a person associated with people with disabilities.

One thing that I got to exercise in this effort around accessibility was the concept of people with disabilities knowing their own needs better than the professionals. And although I was performing somewhat as a professional, I certainly didn't have any licensing. I really considered myself as an attendant who had done good and was rewarded with a position with the university. But I continued to express the consumer orientation for removing barriers: "We don't know what will work here? Well, we have to ask someone." And we would do that, we would go to a specific site with Mary Ann and say, "Look, see, she can't get the door open." And that kind of demonstration, I think, is quite effective in the learning process with people who just aren't familiar with architectural needs for people with disabilities.

The People and Atmosphere at PDSP

Cowan: Were there other issues? Did people in PDSP meet a lot--you know, Zona and John and you or whoever--and say, "What issue should we work on next?" Was there that kind of developmental discussion going on, that you remember?

Dibner: We had regular staff meetings. I wasn't involved in the overall direction of the organization--the Disabled Students' Program--except for the fact that there were only a half dozen people there and so everyone had that much influence.

The staff meetings were the main focus for how we are doing, what do we need to do next. And there was a lot of discussion at those meetings about, "Well, here's a new problem. How do we solve it?"

There were also social events. And there were things like we painted a mural on one of the walls. It was a giant rainbow in--there was a central meeting room. It was like the dining room and conference room and counseling room, at times, and reception area, so when you came up that long, steep ramp, you came right into this gathering room.

Cowan: This was on Durant?

Dibner: On Durant, behind Top Dog, yes. And so one whole wall of that room got a big rainbow with a blue sky and clouds behind it, a painting that was an effort of a group of people: the staff and members of the disability community and friends.

The rainbow, of course, symbolizes a lot of things to people. At that time it was--what's the word?--it was current. It didn't have some of the more particular meanings it has now. It just meant growth and progress in a way and happiness, I think. And having that mural was kind of a tone-setter; it took a somewhat dreary apartment and it made it more interesting to convene in.

At the same time, at the top of the ramp there was a large landing, a wooden platform about half the size of this room--say, ten by ten or something like that. And the landing was quite an adequate space to hang out at. Just behind the landing there was a persimmon tree that drooped right next to the landing. You could reach up and pick persimmons. And although this was a back parking lot between buildings, it was kind of an interesting place to congregate. It was off the street, it was fairly quiet. There was noise all around from the avenue [Telegraph Avenue] and Durant and adjacent buildings but it was actually quite a good place to congregate. So I do have images of Hessler and other people--Michael Fuss, myself, Zona, just sitting out on this patio, on the landing of the ramp discussing things--you know, how's so-and-so doing or whatever.

That landing was adjacent to the room that had the rainbow. And there was a big, large window that slid up and down. Actually, some people would go in and out of the window sometimes.

Cowan: Who else do you remember? John and Zona and Mike Fuss and do you remember other people--staff?

Dibner: I said there were five or six people. I wonder who the others were? Oh, yes, not Dennis Fantin, there was--David Konkel I think was involved as a counselor. Who were the counselors? Carol Fewell worked there for sure.

Cowan: What were the other jobs? You were the housing counselor. Were you a counselor in another sense--in a sense of helping with other issues in people's lives? Or mostly housing?

Dibner: No, everything. Everybody did everything. We had our specialties. Michael Fuss focused on wheelchair repair. I guess. Chuck Grimes was there in the fall of '72. And Andy Lennox was there. He was driving; he was an attendant.

Cowan: Well, it's good to have this on a tape.

Dibner: Yes, so Hessler was director. Don Lorence was there as assistant director at the fall of '72. Dennis Fantin, who was a blind man, did counseling and advocacy. Chuck Grimes is listed as counselor, also, but he was mostly doing the work on wheelchairs. He aided with activities of daily living and making equipment, which was a fix-it kind of thing, but also it was the kind of thing which today is called rehab engineer. You look at the individual's situation and the functional need to get from point A to point B or to reach something or turn a handle and you create a lever that the person can grasp. That was the kind of stuff Chuck and I worked on a good deal.

In the newsletter it says, "Eric's duties are similar to Chuck's with the exception that he specializes in finding suitable housing for students," so I guess I got to do most of the housing search.

And I kept the office open during the weekend but everyone had to fill in for everyone else. When someone came through the door, figure out what needed to be done. There was no one who was properly the receptionist. I don't think we had secretaries.

Cowan: Were the leadership roles John and Zona, mostly?

Dibner: Yes.

Cowan: Or was there no leadership? Was there a structure hierarchy?

Dibner: Well, there were only five or six people when I started there and that's not much of a hierarchy. And these were all people who sat down together and talked about things.

The large meeting room was used for meals. And this was the era of communalism and the open door household and crash pads. Zona would cook in the kitchen, often, or others of us might. Zona often cooked a big lunch, made a big pot of bean stew or some kind of stew. I don't know how much you know Zona--she just loves to cook. She did a lot back then, so there'd be a pot of stew there. And people would come over at noontime, sometimes.

So even though this was an office, it was actually a second home for some people. And the counseling that went on was more or less atmospheric than direct counseling. It was kind of a welcome mat approach.

Peer Counseling

Dibner: Many people did request or require certain kinds of particular, if you will, psychological counseling. The peer counseling model got very clearly established after the Disabled Students' Program.

Peer counseling consists not just of the psychological aspect but dealing with problems of living. And how do you solve these problems? When someone was having trouble matriculating at the university, it might entail convincing the admissions office to deal with their application a certain way. It might entail working with that person on developing a specific skill. It might entail getting a note-taker to assist the person in a class or in taking a test. It might entail not just skills development but also saying to the person, "You can do it. I've done this before. I've got a similar disability to you and I got into that class and I showed the teacher how to help me do the lab work."

So that kind of peer counseling which was a holistic approach was fleshed out in the Disabled Students' Program, although you can see the seeds of it were back in Cowell Hospital where everyone was lending a hand to everyone else.

Cowan: Yes, but this was pretty innovative--peer counseling?

Dibner: I think there were prior models, not out of the disability movement, but there are prior models for peer counseling which I can't cite. I don't know if Zona was in school at the time--Zona went back to school and was studying for a counseling degree. She's got a master's in family and child counseling. At some point she went back and I don't which is cart and which is horse here.

Components of the Independent Living Model

Cowan: What about attendant referral, did that happen in PDSP?

Dibner: Yes, we would help people find attendants.

Something that was growing in the Disabled Students' Program was the model for what an independent living program is. The components that were described in the newsletter were helping people find attendants, helping people with housing

services, not necessarily finding the housing for them--which would be nice but it's just such a chore--but helping people with housing counseling issues, transportation--providing transportation--because you couldn't get on a bus back in 1970-71; you couldn't ride a bus if you used a wheelchair--helping people with the peer counseling issues, which were really important for just knowing how to do something and feeling that you can do it. And there's got to be one or two others--helping people with benefits counseling: how to use the system and make the system work. And helping with equipment, assistive technology--like wheelchair repair.

Those issues rolled together really constitute the independent living model which is now encoded in the Rehabilitation Act of 1973. No, I think, actually, that that section came later. I'm not sure.

##

Cowan: We were talking about the program at DSP and the newsletter that you gave me. One of the things I noticed in it was a remark about the National Federation of Homemakers. Who are they and what was their role? Do you recall?

Dibner: I really don't, no. There had been from time to time organizations that people in Berkeley identified as possible sources of attendant services--for training and organizing tools to assist people who were working as attendants to be more--I don't want to say professional, but to legitimate the process.

Self-Directed Attendant Services

Dibner: I haven't seen a program that ever worked. When attendant services became a state program in California, it was set up on a very non-certified model. Each county was able to set up their own program. In Alameda County, after you established how many hours of attendant services you would need, a check was written to you for that number of hours after the attendants had done the work. You hired and fired your own attendants and trained them.

The idea of having a trainer from outside--a trained person do the services--was somewhat antithetical to the concept in Berkeley amongst the people who were part of this movement. The idea was that you needed to describe

particularly your own living needs and the services you needed to have performed. Like for one person it might be brushing your teeth for you, for another person it might be handing you the toothbrush, and for a third person it might be setting the toothbrush into some kind of holder. And the holder had to be just in the right position so it would fit your hand.

I think John Hessler used a power toothbrush. He had to have it in his hand in just the right angle for the bristles to be facing his teeth because he could only hold his hand in one position up to his mouth.

So if you went to school and someone told you, "Thou shalt do tooth-brushing this way," you would have to unlearn all that when you got to work the job.

O. Dibner: You have to be willing to unlearn it also.

Dibner: And you have to be willing to unlearn it. So the real lesson is to be responsive and open to what the individual is ready to ask of you.

This is a constant problem around the country. My mom, for instance, in Maine is receiving home aid services right now. She has Parkinson's. And she isn't good at giving orders. She never has been good at describing what needs to be done for her; she just knows when it's not right and tells me about it. The people who come to her all trained, they say, "Well, we'll put all the cereal on the top shelf and all the hamburger in the freezer." And she doesn't like the hamburger in the freezer or whatever, so it's very important to be self-empowered and know what your needs are and be able to describe them.

Empowerment was obviously a term of the era also. Self-direction was an important aspect not just of the disability movement but of the mental health movement at that time, and of course, just witness the movement of free speech--and free everything else that we've been discussing. The aspect of disability reflected the social mores of the time, the growing libertarianism of the time.

Cowan: The newsletter also mentions something about the "proper quad attendant etiquette". [laughs] That seemed like an interesting phrase to me and I wondered--

Dibner: Does it describe it? [laughs]

Cowan: It does in a way. I wondered if you remembered if there were issues that would be hard for attendants? Did you notice friction between attendants and people with disabilities? Was that a problem?

Dibner: Well, I think there's a natural tension between any supervisor and worker. And there's also the historic stereotype of people with disabilities as being someone who you can help if you just reach out and help them. And that translates sometimes into doing for rather than responding to what someone needs.

So the tension--of a person with a disability trying to describe to someone who's able-bodied and thinks they're on top of things how something should be done--is just a natural offshoot of their relationship or of social upbringing.

That is something you need to unlearn in order to respond to someone, but the person with a disability may come from a dependency realm, also. They may have been constantly beset by nurses and other health practitioners or family who would always--they would take the person's will away, in a sense; they would make decisions for the person. In a lot of cases people have become incapable of deciding things, knowing how to make decisions about their own life or knowing how to direct their own life as a result of the institutional process. I mean, anyone who's been in a hospital knows how this can happen to you. You are a victim, you must behave according to the standards of the institution that you're in.

Cowan: They have something to unlearn, themselves.

Dibner: So people with a disability who weren't strong individuals, who had already overcome or had never succumbed to that, needed to find ways to direct their own care. So, that tension was there.

I think one of the reasons why there hasn't been a national organization of attendants is partly an effect of the individualized nature of the service that's provided; the fact that the employers are themselves only individuals, they're usually not organizations.

Now there is an organization in California which is affiliated with the Service Employees International [Union], I believe. There are organizations in some states where there are a large number of people working as attendants.

At one point we tried to set up an attendants' union. I worked on that for a year or two.

Cowan: Really?

Dibner: Yes, with Bronson Lehr and other people. But the independent nature of the attendant, also, contravenes this process. They don't want to be organized. Many of us--like the fact that you work a few hours and go home. You can set your own pace in response to the needs of the people you're working for. You can make your own schedule in a way, and work out hours. People were not into being organized.

Cowan: Did the peer counselors help with that? I mean, if an attendant and a person with a disability got into real trouble did they go to a peer counselor, or did they just dissolve the relationship and look for another attendant?

Dibner: No, I think that peer counselors were very important in that. A lot of people would not know how to train an attendant and this is still a service at CIL. This is a problem in Berkeley right now. There is an attendant services crisis. People who don't know how to manage their attendants are failing to keep a regular stock of attendants to provide the services they need. And as a consequence they're depending on this emergency service called Easy Does It.

There isn't a training program. The peer model isn't there. The community is so widespread now. There are not just a handful of people to deal with, so although some people may get peer counseling, others don't.

There's always going to be a group of people who just don't know how to do stuff or who don't get it together, but counselors, people who had disabilities, would advise and say, "Well, you should be doing it this way, try this or try that." And I must say, the attendants in the early days did a lot of this training. I think we had some good, sensitive people. The group of people who were working at the Disabled Students' Program, most of them were "new age" sensitive people for that era, and were forward thinking, and also realized what the peer model and attendant services and independence meant. We all tried to push that concept however subtly or directly it needed to be done.

Cowan: Were you all aware of how innovative this all was?

Dibner: Yes, I think we were aware that the model was a new model. And the way to replicate--to keep it going--was to talk about it. We did talks, we went on trips to other places, we talked in other organizations.

Cowan: You were providing the housing counseling for students who were moving out of Cowell or out of the dorms?

Dibner: Well, you know I don't remember where they lived, honestly. I think fairly quickly after '71 there were a goodly number of people who lived in the community. It didn't take long for the half dozen people who had been at Cowell to multiply into several dozen who were under the wing of the Department of Rehab. And there were some people who came in who had nothing to do with Rehab, but by and large it was Rehab who was providing a pipeline of individuals into this process. The Disabled Students' Program was cranking the pump to keep those people moving through the system, also, so the number of individuals who needed assistance and needed services and who were getting into school increased rapidly.

But remember, the course of school is only three or four years, so some of those people had already gone through the system. Hessler, Ed Roberts, and probably most of the other people who had been at Cowell, when I knew them, were either dropped out or graduated. They didn't all come in their freshman year. Hessler, for instance, had gone to a community college before then.

Cowan: Did you notice a resistance in the community to the people with disabilities moving out and into housing and living independently or living together? Or did you notice any community response?

Dibner: I think there was some landlord or manager discrimination when someone applied for housing, but it wasn't an epidemic of discrimination. I think more of the problem was barriers in the buildings. I don't remember a lot of resistance from landlords. I certainly don't think the student community was resistant. There were so many things going on that this was just one more decoration on the wallpaper as far as activism was concerned.

III CENTER FOR INDEPENDENT LIVING IN BERKELEY, 1975-1982

Genesis of CIL

Cowan: At some point in there CIL was beginning to form up. In the newsletter, you mentioned that Zona and John are talking about that--to provide a service that is not just for students but for people with disabilities in the community at large. Do you recall talk about the seeds of CIL?

Dibner: Yes, well, I wasn't involved in that, but I do remember it. It was some of the conversation around the lunch table. There may have been meetings at the Disabled Students' Program. I think there were some meetings at the Disabled Students' Program, but the CIL people had somehow located an office in an apartment on Haste Street and were starting to work out of it to try and take some of the load off the Disabled Students' Program who really couldn't serve people who were non-students. The Disabled Students' Program had a pretty open door but would tell people who weren't students, "Students come first, we have to provide services for them." It was always a scramble to keep up with the number of things that people needed as in any service program. The need for a service program for people in the community who weren't associated with the university at all was real apparent.

So this newsletter we've talked about was November of 1972. That to me means the Disabled Students' Program had been around at least a couple of years. I think that people had been discussing a Center of Independent Living for over a year at this point. They were already providing some services out of that apartment.

Cowan: Whose apartment was it?

Dibner: Well, I don't know who actually rented it, to tell you the truth. CIL wasn't incorporated until '72, I think.

O. Dibner: It mentions there that Biscamp was meeting with John and some other people, so we must have been working on the by-laws at that point.

Dibner: The people in the CIL process were overlapping with the people involved with the Disabled Students' Program. Even though they were different, they were part and parcel of the effort to develop independent living for people with disabilities. One of them just had a university focus and was a little older.

Now, all these people, or some of the people in these groups, were working on the Rehab Act Section 504 of the 1973 Rehab Act--which eventually became the first law that really affected independent living and the right to access. That law was signed in 1973, although it took several years to get federal regulations published and signed to implement it. The Rehab Act was being developed at the same time that CIL was forming and starting to provide services. So Zona and Ed and Judy Heumann and others were working on the development of the national legislation to support the independent living model.

They had started working on getting an RSA [Rehabilitation Services Administration] grant to fund the Center for Independent Living. And in order to get the grant, they had to be incorporated. Working with RSA, Herb Leibowitz was one of the principals here. Fred Collignon might have been involved with incorporation or with the grant. But in working with RSA they got to know who key people were. Herb was one. Those people became attracted to what was going on. They'd say, "Oh, there's a little action going on here that means something." And so they incorporated--not just working on the funding for CIL but they incorporated this concept of freedom of choice and the right to access into the Rehab Act of 1973. As you know, legislation takes a couple of years to get through the Congress and it was all happening at the same time.

Cowan: The newsletter mentions that [President Richard] Nixon vetoed the Rehab Act in 1972. So was it reworked and then passed?

Dibner: I don't know how much it changed in that year. Yes, it was obviously the same law and they just went ahead and got it passed over his veto.

Cowan: Do you know anything about how the first funding came for CIL?

Dibner: No I don't. I know Ruth Grimes worked on that. Herb Leibowitz and Zona and others worked on seed money from RSA.

Cowan: At some point you moved over from PDSP to CIL, yourself. What led up to your moving over?

Dibner: Well, that was several years later, actually. Let's see, this is '73 we're up to. I was, as I said, hanging out at the green house trying to make a creative life where I could be artistic and write. The house on wheels was my ultimate creation in a way.

We were working on quilt projects, where a bunch of people would work together on a quilt. We made a quilt as a present to Zona at one point. Walter Gorman was doing a lot of attendant work, also, and he was a quilt designer.

I took poetry classes. I took classes on this stuff called body alignment, which was a kind of yoga and movement exercise thing. I took a class in comedy and mime. So I was trying to just grow as an individual without losing my yen for learning in an organized way. I was still trying to do things in an alternative way. [laughs]

In the spring of '73 I took the truck down to Camarillo State Hospital where a friend of ours was working as an intern, like occupational therapy. Her name was Kalya Cotkin. She said she had some entree where she could allow me to come there and study the institution, so I did that for a week or two.

I parked the truck down there in the staff parking lot and just explored around the state mental institution. That opened my eyes further to the idea of the problems of institutionalization and warehousing and what kind of treatment you get in that kind of setting.

I had never lived in that kind of setting other than a very liberal summer camp for boys which is certainly institutionalized. I have never been in the army or the service or really experienced that. Oh, I went to school for twelve to fifteen years, [laughter] but under a locked door situation it's a lot different.

One of the books I was reading at the time was The Origins and History of Our Institutional Models¹ which is a really good book out of Syracuse. Syracuse University did a lot of things around health issues, mental health issues, and issues for people with disabilities, including developing access standards.

¹Wolf Wolfensberger (Syracuse, New York, Human Policy Press, 1975).

Even though I had been involved with the Campus Committee for Removal of Architectural Barriers and the Disabled Students' Program, I was still very aloof of being a part of the university--part of the organized system.

Working on City of Berkeley's Housing Committee, 1973

Dibner: However, in the summer of 1973 after I came back from this little stint in Camarillo, I got involved in housing issues in the city of Berkeley. When I lived with Scott, I was involved in a rent strike that was all around town. The activism of the Berkeley Tenants Union had become very organized. I had read a lot of materials on the housing market. So I started to get involved with the housing committee. The city of Berkeley was rewriting the housing element of the master plan and wanted members on this public committee. There was a drafting process for this housing element, and I was on the housing committee for several months working on this draft and trying to include in it some elements sensitive to the housing concerns of people with disabilities.

I don't think we did a great job. We did mention it, but housing elements in general are just a framework for--it's not even a framework for process, it's just an overall planning tool that, you know, gets put on the shelf.

Cowan: Were you a member of that committee as a representative from DSP or just on your own?

Dibner: Yes, I just walked in the door. Hale might have been on that housing committee. I think he may have. I don't remember. Hale was someone I was getting to know better. He was involved in municipal activities as an activist for as long as I knew him. Before I knew him, he was a student at the university but he wasn't a part of the Cowell program. He may have come in and out of the Disabled Students' Program but again he was someone who was quite independent in his own right despite the severity of his disability.

He hadn't depended on institutions. The institution that had kept him out of institutions was his family. His family was quite sensitive and not overpatronizing and provided him a healthful outlook where he was able to get along without a lot of support from other organizations.

##

Cowan: So you were on the housing committee but you weren't there as a representative of PDSP?

Dibner: Right. I was seeing myself from the community perspective. I certainly took the disability advocacy role on that committee and found great receptivity in the members of the committee, although I'm not sure we made--I mean, that the housing element wasn't any Magna Carta for people with disabilities.

It was for me, though, the first time I had really gotten municipally oriented since I'd started working as an attendant. Now I work for the city of Berkeley and housing issues are still an issue.

Attendant for Hale Zukas, 1974

Dibner: The housing committee, though, kind of got me involved in community issues that Hale was involved in. And I'd see Hale at some things--at events in the community and workshops. And at some point he asked would I like to do some attendant work.

While I was at Disabled Students' Program I might have done some attendant work. I did work at one point for Greg Sanders. I don't know when that was. I might have done some work for Phil Draper. I worked for Greg for a year, I think.

But then Hale asked me to work for him. He was living at home with his mom and his brother and his sister, I think, at that point. I did start working for him--getting him up in the mornings--while I was hanging out at the green house.

I remember at the point he came over to the green house--I was working on the floor of my truck. And he chatted me up about the idea of moving out of his family home into a home of his own. I said, "Okay, sure, I'll move in with you." It had been suggested in a discussion with his mom, who was his primary caregiver, really, that maybe I'd be someone who might be willing to work with him on moving out. And I just said, "Oh yes, sure," like that. Then later he came back to me on the next day and he said, "My mom thinks we're being kind of cavalier about this." [laughs] I just remembered using the term cavalier.

Cowan: But you did it?

Dibner: Yes, and I think it was the beginning of '74 when I moved into 1947 Dwight with Hale. I told him I would do it for several months. I remembered my last experiences with Scott and I didn't want to get into the problem with living with someone when you're the sole attendant.

When you're the live-in attendant you can get trapped into, well, their problems. What happened with Scott was I had kind of ended up as the only person there to help him. He wasn't able to get attendant services. I don't know when the county attendant services started happening, but there was so little; even though you could get something from the county to help with attendants, you got so little that all the person's resources could go into a live-in attendant.

If you're the live-in attendant you've got to get the person up and put them to bed. You've also got to cook the meals and keep the house and maybe deal with paperwork. It can be a real trap. You can end up--as with any dependency situation--in the exact trap that the person's trying to get out of.

So I wasn't particularly interested in spending a long time with Hale but I said that I'd help him move out. And I moved in with him. It ended up taking nine months because he didn't really have his independence together. I was averse to really telling him too much how to do it, but at a certain point I decided I had to start, if you will, weaning him. I told him, "You've got to get someone else to do this. I'm not going to do it any more. I'm Mr. Free Spirit, I don't live in traps, you know."

So it was toward the end of '74 when I moved out. I finally gave him an ultimatum. And he did find one of his other attendants to come in and do the live-in work.

One of the things about attendant work is that there are freebies and trade-offs involved in it. The hour is not always an hour long. Some days you go over, you get someone up, they pay you for an hour and it takes forty-five minutes. But they didn't pay you to come over--the time it takes to travel--and in an hour or two hours work, if it takes you half an hour to travel, that's a pretty big contribution.

In a live-in situation, it's even hazier, because you're working for someone, supposedly, to do specific tasks, but when you're there the person asks you, "Can you get that book for me?" Well, of course you get them the book, right? So you're working on a monthly basis of you know, I get my rent free and

that's worth so many dollars and equals so many hours, but you know I'll do whatever's needed. So there is this sliding scale that happens which makes the relationship intrinsically difficult. I don't proffer a solution for it other than trying to be clear about your relationships.

With Hale it was difficult to be clear. Hale is reticent to speak and also has a speech impairment so getting clear answers from him was always impossible. And that was an unfortunate aspect of our process of learning about each other. [laughs] I just had to get out of there at some point, so that was around the end of '74.

Cowan: Were you simultaneously working with him on housing or access issues and being the live in attendant? Was that happening together?

Dibner: I was trying not to. I was making a specific effort not to get involved in these kinds of things--the things he was involved in. I had done the housing committee stuff. I was helping Hale with a lot of his community activities because he needs hands to do things, just to set a book up so he can read it. When he would get a report, I would open it up for him and sometimes turn the page. He's very busy, so while I was feeding him dinner, often he would be saying, "Turn page," you know? He can turn the page himself at times, but when he's eating he can't. So I'm there looking at the documents. I can keep track of what's going on.

When Hale needs to make a phone call, he needs someone to speak for him. He can spell on a spelling board but he needs someone to speak for him. So when I was assisting with a phone call, I was becoming intimately involved, as his voice, on a particular topic of concern.

He was working at CIL or he was at CIL. I don't think he was being paid, but he was an advocate in the community affairs division of CIL, which he kind of hacked out. He must have made some arrangement with Ed where he would say, "I'll deal with community issues," and Ed said "Go for it." So suddenly there's a community affairs department. Many of the issues Hale was dealing with were accessibility--getting the city to design curb ramps correctly and start to install curb ramps, to invest money in curb ramps, to make buildings more accessible.

Hale worked a tremendous amount on transportation issues. He was also into bridges. He did some consulting on bridge designs.

So this is really how I got dragged into CIL. As much as I was denying my involvement with it, I was actually quite involved with it before I wanted to admit it.

Hale was my mentor in that. He helped me understand a lot about accessibility issues and a lot about policy and how designs are developed and how engineers work on those designs and how access solutions have to come through a policy process in order to hit the ground and actually be poured in concrete.

During that time, though, I was, you know, trying to keep most of my feet out of that pond. I took courses with people at the green house. I still spent a lot of time at the green house. It was kind of an escape from being in the house with Hale where I knew I'd be asked to do something.

I don't want to badmouth Hale, [laughs] it's just there aren't enough people around to be your hands, your mouth, and your secretary, and do all these things for you. Hale wisely uses the resources that are available there. He asked many people to do things for him when they're present, and it makes people feel used sometimes.

Cowan: But he was your source of income at this particular time?

Dibner: That's correct. I was living there and I didn't really have to have much source of income because he was buying the food and the rent. What more do you need?

I was taking courses through community colleges. I took a book-binding course for several years with Walter and learned how to do books. I took a story-telling course in San Francisco. I was really trying to stay creative and not get into the municipal and bureaucratic stuff.

Going to Work for CIL, Spring 1975

Dibner: You want to know how I got to CIL? The Center for Independent Living was on University Avenue. In the fall of 1974 they had an office on the second or third floor of this old building--I think it's called the Kroeger Building--on University.

There was a study going on and Hale was involved in the study. Fried Wittman had a subcontract with a consulting firm to study BART--BART had just started rolling--and why wasn't BART being used by people with disabilities?

Well, Hale was involved in this. They needed people to work on this study, interviewing people with disabilities. So I started going to Center for Independent Living as a consultant to work on this subcontract that CIL had with Fried Wittman.

We interviewed a bunch of people. We developed a questionnaire. Ken Stein and I were the principal leg people doing the work. Hale was overseeing the work and putting the concepts down. I typed the report. And that was my first real work at CIL in spring of 1975.

From that point I was--I wouldn't say entrenched, but I felt that I was part of the extended family. I made some money doing that and I just continued to stay with CIL.

I said to Ed, "What we really need here is an organizational chart." I tried to figure out how CIL was functioning, what all the departments were, and who did what. And I started just hanging out and trying to make a role which I didn't know what shape it was going to take.

I would go to meetings with Hale, so I was seen at times at meetings where I was the one doing the speaking. Hale was the one making up the words, but that helped me to vicariously be a participant in community and other kinds of activities.

CIL moved to Telegraph Avenue in mid-1975. The offices they were in [at 2054 University] were really terrible. It was this really kinky hallway--very tight turns and tight doorways --an ancient elevator, and they had outgrown the size. There were probably twenty-five regular people working there at that time providing services.

Growth and Commitment at CIL

Cowan: Do you have any thoughts on why it grew so fast?

Dibner: Just so much to do. People would come in and it's like the way a cancer grows--I hate to use a negative concept--it had agglomerated--which isn't the way a cancer grows. Things would get attached to it and build its size.

I remember Peter Leech came in as a counselor and he created a section to do psychological services, right? Someone would come in and they'd write a grant and they'd get some

funding. I don't know what the grants were that it was operating on at that time. I just don't remember, but we'd done a contract, I remember, with BART to study why people don't use BART. Suddenly you've got Eric Dibner and Ken Stein as people there who can answer other questions also.

Ken did continue to work there as a regular staff person. The people who were able-bodied who weren't the consumers, as it were, ended up having to do lots of different things for lots of different people because many people could not use their hands or would need assistance getting to a meeting or something like that. So many of the more menial or physical tasks fell to the people without disabilities. Anyone who was willing to get in there and pitch in would get their foot in the door. It was a good way for people to gestate new roles because people were needed.

The way really got connected to it was when we moved to Telegraph. Ed asked if I could assist with the move. I kind of coordinated the process, the physical process of getting everything organized and designing the new space and working with the movers.

Cowan: Right up your alley. But still, you--people--could have moved on. They could have done that little BART contract and then gone somewhere else. Why do you think they chose to stay with CIL? Was there a sense of commitment?

Dibner: You mean Ken and me?

Cowan: For instance, for example.

Dibner: Yes, right, I think we did. Let's take the people who were from the school of architecture, though. Fried and Ray Lifchez both had something to do with CIL and I think they were both at the University of California. Fred Collignon is at the University of California. They had positions of professional stature already. They worked with CIL for several years, each of them. Fried not as long as the others, but Ray worked for three years doing things with CIL and developing groups. He never worked at CIL, he worked at the university. CIL was a test tube to him. He developed--he took some of the concepts and he grew them into architectural concepts. The peer counseling model became the consumer design model: we can design our own homes to meet our own needs. Housing right now isn't suitable to people with disabilities, so he developed a whole model for how you design housing based on the peer counseling model. And Fred Collignon helped a lot with the political structure and organizing CIL to work with government

in a good way. Those people had other positions to stay with, I didn't have another position. Ken also had gravitated to this organization.

I think part of the virtue of it is you're serving. You're providing a service to people.

My dad always said to me, "Well, what are you doing this for? Why are you working with those poor disabled people? I mean, isn't it depressing?"

Well, the fact was it wasn't depressing. It was invigorating to know that we were not simply creating a new model, but we were creating success by finding out ways to do things. That was the interesting thing. And the fact that CIL as an organization was still trying to do that, also, was attractive in and of itself.

I don't want to say do-gooder, but it's a good thing to do. It's got noble results and it's got results that you can see, sometimes. Where you build a ramp or you open a door, you know that something has been accomplished, whereas a lot of work you do, you're not sure exactly what the end of it is. That was the attraction for me. I can't speak for Ken, but we were two of the bodies who were there to serve and figure out what needed to be done.

Struggle for an Egalitarian Structure

Cowan: Did you ever do that organizational chart?

Dibner: Oh, yes. [laughs] For me, it was a process of learning about process. I tried to get every--we were trying to be egalitarian--don't force anything down anyone's throat, you know, so I created a chart of all the people who were there as I saw the organization and said, "You know, let's try to show what all the connections are between all the parts and you show which people you actually work with," because we were trying to create a structure that was true to the organic structure. It resulted in an organizational chart that wasn't ever particularly adopted or anything. But I thought I was trying to learn about organization and this institution that had formed itself--how was it organized, what did it do. We've got those organizational charts and the lines drawn all over them in one of these boxes.

As far as drawing lines, later on at CIL when we went on strike, it was the able-bodied people versus the disabled people!

Cowan: When was that?

Dibner: It was in the eighties under Michael Winter's aegis. There was some struggle over some of the positions wherein a woman who had good skills wasn't hired for a job.

And Michael said, "Well, I hired the person who had a disability because it's more important to hire people who have disabilities."

And that was one of the precipitating issues in the schism. He said, "Oh, all you able-bodied people are just trying to take over," which did a great disservice to our ennobled profession, right? [laughs]

At that point we went through this long period of struggle of trying to shape the Center for Independent Living into a fashion that was truly egalitarian and was not in the traditional model of the top-down structure, the pyramid, and was more in the model of the circle. And I worked on organizational charts at that time.

We had a union. We tried to form a union, and the people who were administrators tried to squash the union. They did not want to see the workers organized, perhaps fearing they would lose control of their organization. Many of the people who were able-bodied were involved with the union, but so were some of the people with disabilities. There were a lot of problems because of this struggling nonprofit corporation without enough funding and too much stuff to do. Workers were being taken advantage of and maybe that's of the nature of growing movements in general.

There were a lot of volunteers, and no one was getting rich there, but we wanted to have a voice as workers. That was seen as the workers movement trying to squash the disability movement. People might argue that that wasn't how it was seen, but that's how it worked out. We ended up going on strike for something like three weeks. We picketed the Center for Independent Living. And that was never resolved, although the NLRB [National Labor Relations Board] found the administration had violated our organizing rights.

In fact, from that point onward the Center for Independent Living deteriorated. From the eighties onward it

never really regained that momentum. Things splintered, groups went in different directions, and now the Center for Independent Living is a shadow of its former self.

The time I was talking about there were almost 200 people working at the Center for Independent Living.

Cowan: When it moved to Telegraph Avenue?

Dibner: No, in 1981 at the time of the strike it had been on Telegraph for several years. Yes, we got too big for our britches and it wasn't really a community organization anymore. And that's what we were saying, "This isn't an organization, it's a business, we've got to run it like a business."

Right now there are financial problems at CIL; there were financial problems at that time. The people who were administrators throughout it, as far as I know, none of them ever organized it to work like a successful business.

Many independent living centers, and there are hundreds of them now, are very business oriented. I worked for one in Maine which has businesses as subsidiaries. It's a nonprofit that has for-profit subsidiaries and is very organized and had managed to sustain itself and grow without bursting its seams in hard times as well as good.

So it is possible to have a grassroots type organization, although I must say the one in Maine isn't so much of a grassroots organization, it is a consumer-run organization, fully consumer-run. I mean, it has problems, too, like lots of organizations. But CIL came from a grassroots movement collecting, as I said, agglomerating people from around the country, and around the world now, to come to this--what's it called--when something burns in a chemical reaction--

Cowan: Crucible.

Dibner: Crucible, yes. Crucible is the term, right. And it's hard to contain that reaction, you see, and direct it. And that's fine. This is how it happens. Lots of things happen that way, but it's not always fair to the workers. And in my mini-crucible with Hale in the apartment, I had to burst out and that's how things change. Then you're left with whatever's left in the test tube and you go on and create a new reaction.

Cowan: Well, when it moved from University up to Telegraph and you really became part of it, it was not a hierarchical structure?

Ed was the director. What are your thoughts of Ed as the director?

Dibner: Well, it was a hierarchical structure on paper, yes. I didn't know Ed as the director. I tend to carry that along with me on a lot of my relationships. I just thought of him as a friend. I was trying to be a co-conspirator in this process of the growth of the organization--and I was on his coattails of course. I was trying to grab a piece of the action, in that sense, but at the same time I was trying to see where are the gaps here that need a service to be created.

Ed was a colleague in community and disability issues and I never really had to deal with him much as a boss. Hale I really saw as my boss, but again, we kind of worked through things together, figuring out what needed to be done. Never did it feel in the latter half of the seventies terribly much like this pyramid structure.

But later there were so many departments. Some of the departments had eight or ten people or fifteen people providing programs so that in those departments they would struggle to try to recreate themselves.

In my department there were only three or four of us ever. When I was with Hale there were two or three of us. When I worked with the housing department there were only two or three of us. And I had longevity so I didn't have to feel bossed around particularly. We all just tried to figure out what were the services that needed to be done and figured out how to do them.

##

Cowan: Eric, we were talking about the structure at CIL and I was wondered if you have any comments on Ed's role as a leader in the organization?

Dibner: Well, not being a person with a disability I wasn't exactly on the sidelines but I watched this happening as a non-affected individual; it wasn't my rights that were being espoused. Although--well, I shouldn't say that because we quickly bought into the idea that disability is not a special thing. It's something that's a part of society, our families, and ourselves as we age or if something happens to us. So I felt that Ed and the disability movement were doing something for me. So I didn't feel completely alien in that sense, but I definitely felt like I couldn't say in the disability movement how it should be run. It's real important that the disability

movement takes its shape as an effect of people with disabilities organizing and making that shape. So it was natural for me to go along with the direction that was being established. I mean I certainly made some decisions. I helped with the CIL housing department.

And the quality of Ed, to me, wasn't, as I said, as a supervisor as much as he was a mentor. For instance, in setting up of the housing department, I remember I would consult with him as what I would consider a peer to find out, well, we need to apply for these funds, what about doing it this way? He would push you to be independent, do your thing. We were both male and felt, I think, that guy-can-do approach to things, so it worked well for me.

We were discussing off-tape how different people's perspective of the leadership in the disability movement is not always like that perspective I just expressed. The quality of leaders in this situation, not just Ed, but Judy and Ed and others who really came to the fore--well, I mean it's like when you're shooting a basket. In basketball, someone's got to have the ball and put it in the basket. There's always someone assisting. You might elbow your way under the basket to get to it, but there's some people who are standing away from the basket who are on the team but they're not taking the shot and not assisting with the shot. So the idea of some of the leaders who had stronger presences is an effect of that elbowing under the basket, if you will.

And the complaints that we've heard about Ed are that he was chauvinistic or sexist at times. I don't think that's necessarily untrue. I think that he had some characteristics that come with us from the way we grew up.

I also talked about how Judy Heumann was very--it seemed like resentful to the organizing that went on at CIL for workers. Why would workers want to organize? Why are they trying to kill the disability movement?

But the labor movement had been very supportive of the disability movement. And the fact that the administration of CIL would then turn into an administration and not just be a commune--like kind of what we thought it was--it was a comeuppance to all the people who had been slaving, if you will, as volunteers and community participants in the organization.

I don't think it's the fault of the individuals, though. It's real important for individual leaders to take a stand and

to say, we've got to haul this wagon along. We need some people behind there pushing, but we're the ones setting the direction. You can't have a hundred people in the room running an organization and have it move at the rate that this organization and this movement moved.

I've also been involved with other groups, like Livermore Action Group, where you operate on a consensus basis. This was not that kind of organization, so as a consequence the workers at CIL felt, "Hey, we're not getting heard here." And we weren't getting heard. It's because that wagon was going down the road and it's not that we were baggage, we were the wheels. So we had to keep turning and sometimes we were tripping over ourselves. [laughs]

I think it's the social dynamic that leaders tend to be more pushy. And pushiness might have effects in it that aren't really egalitarian. I don't think anyone in this movement that I've seen has been a Martin Luther King.

The difference I think comes from King's sources in a religious approach. This was not a religious movement, although in some ways it's kind of like a religion. It was a social movement just like the movement for rights of an ethnic minority, but it's so much more related to mechanical and financial issues. It's not just about stereotypes, it's not just about social change, it's about bureaucratic change in a lot of ways.

The biggest difference between the people with disabilities gaining their rights and others gaining their rights in other kinds of protected classes is that in the disability movement people need specific supports from society. The problem is always to figure out how to provide those supports in a way that doesn't take rights away from people but grants rights to them and doesn't come on as hand-out. The history of handicap is a hand-out. Otherwise you wouldn't survive.

I mean, hey, in some places you don't survive. You're actually eliminated if you have a disability. That's kind of what we've done by just giving little crusts in the past. Now we're learning that society has an obligation to support, as part of its social service system if there's any social service system, the physically weaker participants. Some of these things don't require any support, some of them are just opening the door. So in that sense the part of the civil rights movement that applies to all people is the same for people with disabilities. We have to open the doorways in our mind or the

blindness from our eyes to see that people with disabilities are just people and accept them as equals.

But on the other hand, opening that door sometimes means the ramp out front. And if we don't take the physical act of removing the physical barrier or providing materials in Braille or getting an interpreter at a meeting so that someone can participate as an equal, then that person isn't in the door, they aren't participating, they don't go to the city council meeting, they don't get to make their speech at the city council meeting. That effort to get the social supports has been one of the biggest fights in the disability movement. It's real easy to write a law that says, "Thou shalt be equal," but to put that into effect takes dollars.

I want to go back to what we were saying about Hale and this dependency syndrome that people can get into and how that reflects in the issue of the unionization effort at Center for Independent Living in the early eighties. On the one hand, people with disabilities are asking for basic supports so they can be equal and on the other hand resenting anything that's a hand-out, wanting to be able to describe what those supports should be. It's hard when you're doing that to also respect the person who's giving them to you. So I think the tricky part is that to a certain degree, the disability movement has depended on some volunteerism and some do-gooders who were doing the right good. On the other hand there's a difficulty about that. It's a very hard system to design where the services are there and provided but they're at the beck and call of the people who need them, yet they come as an entitlement as opposed to some kind of special grant.

So, going back to the image of hauling the wagon, someone's got to be driving the wagon. That is the traditional model of how organizations get going. And how leadership happens is someone really drives it. There has always been some kind of cooperative effort in how the disability movement has formed, there have always been groups of people getting together and talking and communal aspects to it, but CIL didn't stay as a commune very long.

Cowan: At some point, there was a difference. It was seen as a service organization and then as a civil rights organization. Is that so in your view?

Dibner: Well, I think that was--I don't know when that--

Cowan: It was always civil rights?

- Dibner: That's a good question. As I say, I wasn't there right at the beginning, but as long as I knew it, yes. Services and civil rights are intimately attached, yes; you can't separate them. But that both tracks were there, yes--you can't get them both from the same place. You get the civil rights by doing advocacy and education and you get the services by getting funding sources and designing programs.
- Cowan: Do you feel, though, in the beginning that the students with disabilities were not thinking this was a right for them to have access but that it was a need for them to have? Was there that kind of distinction, like there was in the civil rights movement? Not can I drink out of this water fountain, but I have a right to drink out of this water fountain. It was a shift.
- Dibner: I think there was a shift, yes. I don't think it was initially so much a right other than any human being would want to have a drink of water, right?
- Cowan: Yes.
- Dibner: So if I'm in Cowell Hospital and I need a drink of water and I can't get it, it becomes a right all of a sudden. But I need to get someone to get me the glass of water and if--this is very real because one of the things we did all the time was filling people's glasses of water, or getting a straw so the person could drink the glass of water. So the presence of attendants is important to that. It's instrumental in it happening. And at some point, I think, people started realizing it's not just mechanical. If I need to ask for it and if there's any trouble getting it then it suddenly become a rights issue.

This raises another dynamic that I keep seeing which is getting people to turn out to support some kind of effort for a movement or just a request to the city council. What happens is that no one will turn out unless something's being taken away from them. So when I can't get the straw for the glass of water I'm going to say, "Hey, John, did you get your glass of water? I didn't get my glass of water. Let's go talk to Edna and find out why we're not getting glasses of water anymore." And I think every time that happens, it causes people to organize and galvanize against this denial of basic service or right. So that's what was happening when we organized at CIL, we felt we'd been denied something.

But nowadays it's hard to get people to come out and fight for things because so many things are available in this

movement. There have been recent things--we went to the building standards commission a couple of weeks ago--the buildings standards commission is trying to take away some of the accessibility requirements in California and make them weaker. So people would turn out for them because, "They're taking something away, we can organize."

Securing Funding for CIL's Housing Department

Cowan: We might go on then with the rest of your time at CIL before you left Berkeley and moved away. Is there anything you want to add about how your job developed or about how issues were handled?~ Was there any particular thing that you want to comment on before you moved from Berkeley to Maine?

Dibner: Yes. I worked for Center for Independent Living for about eight years and one person who came through the door and started working with Hale and me on community affairs was Jerry Wolf. Jerry and I actually began the housing department. I dealt with ramps and Jerry dealt with the overall operation of housing and helping people find housing and doing counseling about moving into a place.

Jerry and I applied for the first grant to establish that housing department or to fund the housing department and got it from the city of Berkeley. We got \$19,000 to run the housing department for a year, using community development funds. And it was the first grant CIL got, I think, from the community development block grant. And they still continue to get that today, to do the same thing.

Cowan: Did that increase the size of your department--you and Jerry?

Dibner: No, we were already there doing it, but the grant made it feasible for CIL to pay us.

I lived with Linda Perotti in '75 and she was working at CIL and doing attendant work also. She and Kalya were living in this house together on Lake Avenue, and I was staying with Linda. I wasn't paying any rent [laughs] because I've explained my perspective on these things. But finally Kalya got down on me and said, "Eric, you've got to start paying some rent." So I think in August of '75 I actually started paying rent at Lake Avenue.

The connection to CIL is that I just couldn't figure out how I was going to pay rent and Kalya said, "You should get paid for the work you're doing," because I was spending most of my time at CIL doing this stuff. Ed must have been the director at this time. I said, "You know, can I get paid? I think I should get some pay."

So he said, "Okay, I'll pay you \$1000 a month."

And to me this was an unbelievable sum to get paid. And from that point onward I was an employee. That was before we started the housing department, but shortly after that we went and got this money, got the grant up and started doing housing things.

Many times we got consulted by outside agencies wanting to know how to do this, how to do that, what is independent living. From that period there on were lots of opportunities for speaking engagements and writing articles on how to make theaters, et cetera, accessible and this is how you take your expertise and become known for what you can do: because people ask you to do it.

It was not the end of my education but it was where I obtained a degree of ability that I could espouse these things more as an expert than in the past.

Access Issues: The Opera House and the Grocery Stores

Cowan: Susan O'Hara said that she worked with you or you worked with her on access to the [San Francisco] Opera House.

Dibner: Well, yes, we did. Issues and projects came up continuously. Which were the ones you would work on? Well, usually it was whether there was someone already working on something that needed assistance and was enough of a profile and enough of a need to make it a worthwhile cause.

But the Opera House--gee, what do we need to get into the opera house for? Well, Susan O'Hara wants to get into the opera house. She's an opera customer and so that was something worthwhile to her; it could be worthwhile to us. As an accessibility issue it was quite difficult to solve, partly because of the historic and the architectural shape of that building, and the historic and the traditional shape of the

people involved in it. There was major entrenchment against change.

Of course, dealing with people with disabilities when you're dealing with the most conservative portion of the population also has a lot of stigma attached and patronizing aspects to it, so we worked on that for a number of years. I think her work was a lot more of advocacy and moving the people who could do something, and mine was a little bit more as the technical expert, but I remember going to a number of meetings with her. I think they've only just recently made it more fully accessible.

Another effort that came to us was market barriers. Store owners in this area started putting poles around the grocery stores so you couldn't take the grocery carts away. Now these days, grocery carts are pretty liberally allowed to wander the streets. At that time it was becoming a problem for the grocery stores, losing these carts to not just homeless people who needed them but to people who'd walk down the street with them, or leave them in the parking lot and kids would take them and make skateboards out of them or whatever, or just push them into the gully. You still see them in the gully or in the bay and everywhere.

But we didn't care how much money they were losing on grocery carts--people in wheelchairs wanted to go shopping. So Jean Kaiser and Renah Shnaider and others and I organized for, I think, seven years. We wrote letters. I've got a file three inches thick of letters that we wrote just trying to get nine or ten grocery stores in the East Bay to take the poles down.

Finally we threatened a lawsuit. It didn't work, but we finally got the city of Oakland to file a lawsuit. And eventually the city filed a lawsuit against the stores for failing to remove the barriers, and they took them down right away, some of them. Actually the last one to do it was Co-op.

Cowan: So for seven years those barriers stood?

Dibner: Oh, they kept putting them up, yes. And we worked on gates. They tried all kinds of obfuscation and bait and switch--just making it difficult to get into the stores. It wasn't until we actually took the not-so-nice route and filed a lawsuit that something happened. That educated me, too, that you can't always solve a problem by following the pleasant course of action. Sometimes I think the fastest way to the end is to just file suit and, "Let's get on with it." I hope no one does that in Berkeley against me. [laughs]

The people that I was working with in this market barriers suit came from the California Association of the Physically Handicapped. This was the statewide organization of people with disabilities. We had some 3000 people in the organization then. I was the housing chair person for a number of years and was the vice president for a year, also. That organization still exists, but in a different form. It was based on the traditional model of people with disabilities asking for things and being nice. It was a lobbying group so it worked on legislation, that's where its real power was. But because of that perspective of we're going to work with the system, it was very shy of filing lawsuits or demonstrating. But that was one way that we tried to make the process work.

There were other people who came to CIL who had different perspectives on what needed to be done and wanted to file a lawsuit right away. I worked with a number of people in the community--Dan Drake and this attorney, Paul Rein, who filed a number of suits. They just came in said, "Look, let's write a few letters. If the people don't respond, let's get on with it and ask them to make their place accessible."

Marilyn Golden and Access California

Dibner: One person who came through the doors of CIL was Marilyn Golden. I sat right near the doors because Hale and I were in a side lobby right in front of the restrooms. We had a table set up in this alcove which had a view of the entrance.

Marilyn came in. She came from Texas and was looking for stuff to do, and she wanted to know, "What role can I take here." Well, this was an organization with over one hundred people working for it, and I was sure that we were just trying to take on too much stuff. I had been working with Jean Kaiser and other people in Oakland, so I said, "Marilyn, why don't you start a program in Oakland?" And so she did. She started Access California for which I ended up being the chair of the advisory body, the consumer board. This program was in the social services department of Oakland. It was a lot different --it wasn't a CIL, it was a municipal effort to make changes in the city.

Marilyn started curb ramp programs in Oakland. I actually did a survey of a lot of the corners in Oakland. Jerry Wolf ended up going and working for Marilyn. Ken Stein ended up working there. So there was this kind of

transmogrification into a new center. There was no center for independent living there but it was kind of an outpost. And after the strike at CIL I went and worked for Marilyn, [laughs] so that was just pretty funny.

And now, Marilyn's doing a lot of other things. Access California doesn't exist but the city of Oakland does have disability coordinators and it has a branch of CIL now working in Oakland.

Spin-Offs from CIL: Organizing a Movement

Dibner: Part of what happened at CIL was it got too big for its britches. People were starting new programs. There were myriad programs at CIL. There was a branch of Antioch College West started there. Antioch College West, I guess, had an office in San Francisco, a college in San Francisco. We started a program--I didn't start it, someone else did. I guess Hal Kirshbaum and some others.

Cowan: Patrisha Wright?

Dibner: Patrisha Wright. It was a regular college campus and we had courses there. I said, "Hey, I'm going back to school now," and so I started working on a degree in housing counseling. I never finished that because the bureaucracy just started blowing me away again. I had to fill out so many forms and complete things the way they wanted it.

And the law center started across the street--Disability Law Resource Center [DLRC]. I went to work at the law center as one of the trainers in the 504 project. I was still an access specialist but I worked with Johnnie Lacy who later ran the Hayward program for a number of years. Johnnie got the job of running a training program after the 504 demonstrations made the law a reality.

After 504 got signed, the feds agreed to pay some money to train people in the region about their rights and train community action agencies on how they could assist with the implementing. They targeted community action agencies for implementing disability rights at the local level. So we trained in the Western region--in region IX--a lot of local government agencies. The Disability Law Resource Center started growing and it ended up with thirty or forty staff and

eventually turned into Disability Rights Education Defense Fund [DREDF].

Cowan: It started at CIL?

Dibner: Yes. The DLRC--Disability Law Resource Center--was just a department of CIL, technically, then it kind of changed into its own thing.

Wheelchair repair became a program and then turned into Wheelchairs of Berkeley.

##

Cowan: Eric, you were just talking about all the spin-offs from CIL, that the wheelchair department became Wheelchairs of Berkeley. Any other spin-offs that come to mind?

Dibner: At a certain point I think Ed and the other directors started saying, "Well, we can't just keep having new departments." I think that's what happened with the law center. It became such a separate effort that it was real easy to say that it needed to get off on its own, and it did.

Cowan: That became DREDF.

Dibner: Yes, that became Disability Rights Education Defense Fund.

Some things became private businesses, like Wheelchairs of Berkeley growing out of wheelchair repair. And there was actually a van and auto shop in the garage at CIL, but that didn't last past the strike very much. Things started shrinking back at that point.

The basic core services are what started getting focused on. Some things like deaf services are still there, but I think some of the efforts of deaf services have now been absorbed--not necessarily gone to other organizations, but there are many organizations now that provide interpreters. CIL was doing that kind of thing for a while.

There was a program that started--I can't remember what it was called--to try to train young people about how to be independent. And at first I thought it was going to be very patronizing. It was to set up a house where people could come, and I thought they would live there and learn how to live independently, but that's not what it was. The Center for Independent Living was always a non-residential facility. It was always the idea, "You're a citizen in the community. We

can provide support services and counseling and advocacy. You come here to find out what's going on, but you're on your own." So the idea of setting up a house for people to live in has always been antithetical to independent living centers. There are places that call themselves independent living places where the place is the thing. Here, the service was the thing.

So this youth program--I can't remember what it was called, but it was a house that was set up for a while and people did come and they got basic independent living skills training in this household that was set up to be accessible. You could learn how to use a kitchen and basic--it was kind of occupational therapy type stuff. That program didn't continue to grow.

There's probably only three people at CIL now who were there when I worked there. Gerald Baptiste, Phil Chavez, Sandra Feinbaum [Stone]--I don't know who else is still there.

A lot of the people went on and started other programs. Some people have described CIL as a sheltered workshop. People came to get work and do things because you couldn't get jobs in a lot of places and here was an opportunity.

But really it was more the crucible idea where it's a job training place--not job training--it was "organizing a movement" training. People would come and learn, "Oh this is what an independent living program does."

Now Peter Leech has a program in Montana. Sandy Enders runs a program in Montana. Judy Heumann works at RSA [Rehabilitation Services Administration]. I think many people who came through there then have gone on to run other programs. So although the people who came in there may not have been leaders, they could take their small fish learning and become a big fish someplace else by virtue of what they've learned.

One program was a Berkeley Outreach Recreation Program--BORP--which is still here. It didn't really run through CIL very long but Susan [Sygall] and Diane [Schechter] were at CIL organizing it.

I remember when they were talking about it. It might have been in CIL for a year and then they went over to Eshleman Hall on campus. It was never anything other than its own organization but it did get set up at CIL.

Om Devi reminds me that now Susan's gone on and started her own program [Mobility International USA]. But BORP still

Om Devi reminds me that now Susan's gone on and started her own program [Mobility International USA]. But BORP still exists. It's down to one or two staff, but they do recreation programs.

Cowan: Did I understand you correctly that you did trainings for the community? How did you learn to be a trainer?

Dibner: Well, just by talking to people. You're constantly training, right? You're learning from each other all the time. And I'd been around enough that I learned it gradually just by doing.

Cowan: So there wasn't training for you to be a trainer for the 504 implementation?

Dibner: Yes, the 504 project involved more experienced trainers, but by the time we started working on the 504 project I had been doing talks and speaking engagements for quite a while. I think in 1978 I was a presenter in a continuing education class. In 1979 we did a conference on housing.

Also in '79 I did a presentation--a slide show--to the Construction Specifications Institute (and I won a salad bowl as a door prize. We still have it!) [laughter]

The Department of Rehab had a slide show on barrier-free design that Ron Mace developed. Ron Mace is an architect back east. And so, using his slides, the slide show kind of walked you through the process. And by learning what the regs said I could learn how to walk people through the accessibility process using the slides. And by going to a number of trainings myself I could absorb what other people were saying.

Cowan: You left CIL at some point. What led up to your decision to leave CIL?

Dibner: Well, I think the strike was in '81. And after the strike was --I don't want to say resolved, but ended, a lot of employees did not go back. Maybe two dozen--I don't know how many didn't go back, to tell you the truth. But pretty shortly after that people kind of got disillusioned. They said, "I'm tired of this, I'm going elsewhere."

I stuck at it for a while because I didn't have an alternative in mind. I resigned in mid-1982 without any specific plan. But at that point Access California was up on its feet and had some opportunities as a program that I was familiar with because I was on the advisory board, so I applied for a job at Access California. That's not why I left CIL, it

was really as a result of just disillusionment. I worked at Access California for three years--something like that.

Here's an interesting story. Hale and I were both at the disability law center--the community affairs department kind of got plopped into there because we weren't really direct services. And at DLRC, the Disability Law Resource Center, we did a lot of work with the city of Berkeley to remove barriers. We worked on surveying the city's buildings to make them accessible. We had a number of interns from the architecture department work with us for a summer. We trained them on how to learn about accessibility and survey a building. What does accessibility mean? We developed a checklist. One of the people doing the surveys was Julie Zirlin, who wasn't from UC, she was from California College of Arts and Crafts. I don't know why she was interested in this subject, actually, but I trained Julie to help coordinate the surveys. I don't know how she got to CIL, I have no idea. But Julie got very involved in disability and accessibility issues.

The surveys are still in my file drawer at [city of] Berkeley now. I had retained those files because CIL lacked some things in terms of being an organized system. It was kind of a loose-knit system, and the filing systems were not anything to be proud of so I actually held on to some of the things that I thought should not get lost.

When Anne Steiner--who worked at CIL as a job developer well into the nineties--worked at city of Berkeley as the disability coordinator as my predecessor. When I was in Maine she called and said, "Do you know what happened to those surveys?" I said, "I'll send them to you," so I sent her the surveys.

Julie worked with me at DLRC and then when Access California started she went and worked with Marilyn at Access California. So when I went and worked for Marilyn at Access California, actually Julie was my supervisor whom I had initially trained.

Julie worked for the federal access board for a few years and then she went to work at [U.S.] Department of Transportation. She's working on a variety of policy issues--not just disability issues, but economic justice.

We had been working with the city of Berkeley to try to make things more accessible. What was the city of Berkeley doing? Why was CIL trying to make this municipal government do anything? Why couldn't the municipal government do its own

thing? So we talked to members of the city council about implementing the recommendations for access based on the facility surveys.

Actually, Zona's house, the green house, was next door to Loni Hancock's house. And Loni Hancock was a city council member. She was mayor later on. So we knew Loni and she and others who were on the city council were sympathetic to disability issues. So we tried to set up a disability commission.

"Oh no, no, no, no. We'll have a mayor's task force." So the mayor said, "I declare that there's a task force on people with disabilities." I was the one who got that going and started it rolling. Michael Pachovas was also involved in it. He and I were both chairs at one time or another. Susan Ferreyra was on it, Mary Ann was on it, Gerald was on it, and I can't think of who all the people were on the task force.

They assigned staff to it, but the city was always flaky about who the staff would be and it was really hard to make this system change. The city of Berkeley's bureaucracy was notorious for being difficult. We still have a bad rep now but I think it's something several city managers have been trying to change and be much more customer oriented.

IV WORKING ON DISABILITY ISSUES IN MAINE, NEW MEXICO, AND BERKELEY, 1985-1999

Dibner: The mayor's task force on persons with disabilities lasted for a number of years. At that time Om Devi and I had been together for a while, and we decided we would move back to Maine. That was 1985.

Seeking a New Life in Maine

Dibner: I had family in Maine, and my family was getting older. And we were looking for a new venue, a new life. And I wanted to get out of disability stuff, I didn't want to spend my whole life in the phys dis biz, although being intimately related with it, I thought that I might have better opportunities if I was looking in other fields.

In Maine, I looked for year, lived at my dad's, and then when Om Devi and I moved into this farm--we tried to create a kind of a cultural center at this farm. It was a cultural healing and environmental center on this beautiful 103-acre farm on the top of a hill. We could see Mount Washington and lakes and it was just gorgeous.

O. Dibner: We did develop it. But we couldn't get the funding, the backing, to purchase the place, and most of our programs were dependent on that.

Dibner: We did a lot with volunteers. I had learned a lot about how to organize, how to put programs together, and how to incorporate a nonprofit, but I had no idea about fundraising, which is a very special kind of skill. I still have no idea about fundraising. I had gotten a grant from community development so I thought I kind of knew something, but I didn't. You're asking people to pour money into something. It's very

difficult. My dad was well attached in Maine to various funding-type people and we tried, Om Devi and I tried.

We actually had a very egalitarian government. We had a real circle organization. It was so democratic that we screwed ourselves by trying to get so much input.

And now at the city of Berkeley I'm involved in some of these working groups, and the ones that have been trying to be so, so democratic, get everyone's opinion, you just get burned out. You really need the democracy and then you need someone to pull you into the next level of existence. You can't keep discussing every t and i and expect that you're going to move.

So in Maine we discussed the t's and i's and we had a beautiful organization. And the energy just went out of it. And we didn't have the money. And Om Devi and I had some relationship problems, and she came back to California.

Well, at this time I also had gotten a job. Right at the time we moved into Arcadia Farm, I had finally found a job. Actually I had a part-time job before that. I worked in municipal government in the town of Casco, which is a real small town. I got a job working for the planning board and the zoning appeals board. Most communities have these kinds of boards. I was the secretary so it was a continuation of some of the roles that I had had with organizing meetings. My roles weren't technically secretarial, but a lot of what you're doing is providing--organizing--the secretarial material. Organizing a meeting is being a secretary, really. But that was just a little five-dollar-an-hour job. I did that for a couple of years in Casco and learned a little about municipal government again.

Working for an Independent Living Program in Maine

Dibner: And then I got this job--lo and behold there was an ad in the newspaper for an accessibility specialist at the independent living center. So I figured I better apply for that!

Cowan: In Maine?

Dibner: In Maine, right. This was a statewide organization. Maine being a sparsely populated state, most of the varied people who live in Maine lived in southern Maine where we were. The

independent living center was strongest there, but it had outposts in northern Maine.

It was a very well-run organization that was growing at that point. We did a lot with accessibility. We fought some major legal battles. We set some precedents around theater seating and worked on a miniature golf course to force them to make this miniature golf course accessible. And it was like, "Why would a disabled person want to play miniature golf?" You know? And it's the same old story all over again.

Alpha One, the independent living center, is still in Maine. They had just won a supreme court battle over making the bus system accessible in South Portland when I started there. I got to help with implementing that process--making the bus system accessible, and training the drivers, and training people on how to operate a bus system, and training disabled people how to ride the bus.

We made a video, worked with a community college and developed this video. And now the chair of our commission on disability here in Berkeley is using the video that we worked on in Maine.

O. Dibner: [laughs] I'm in the video.

Dibner: And Om Devi's the star. In Maine there's a group called the Maine Association of Handicapped Persons [MAHP], and Om Devi was on the board. The Maine disability movement was going through a major turmoil because Alpha One was an independent living center much more conservative than MAHP. Maine Association of Handicapped Persons had brought the lawsuit all the way to the Supreme Court of the United States on making the buses accessible and won, but they totally exhausted themselves. They weren't a service organization, but here was Alpha One being Mr. Conservative over here, saying, "We're just going to fit into the mold and fulfill the service model and you guys do the advocacy." So Maine Association of Handicapped Persons is left trying in a very, very poor state to raise money to do advocacy services. They went through a lot of turmoil and ultimately collapsed.

The court had ordered that the Maine Association of Handicapped Persons be a party and a participant in the development of the lifts. Remember, they'd just gone through this major legal battle. And the bus system was totally antagonist. They had refused to put lifts on their buses.

So the independent living center where I was working got the contract to do the community relations and to be the go-between between the Maine Association of Handicapped Persons and the transit district. Om Devi was on the board, so I started working with the people at MAHP.

And some of the staff I had to work with, although we liked them at times, just flipped out--they'd go crazy! They started yelling and screaming at meetings. So I learned a lot about community relationships and working with difficult people and trying to solve impossible problems.

I worked with the transit district in that area, not just for South Portland but for the whole region on their 504 plan. They had an advisory committee.

At this time, I'm getting involved in a lot of state politics issues, learning about how government works, and I'm a far cry from the loner that I was in trying to make just my own ends meet. And still we were just trying to make our own ends meet--so I had kind of dropped out and dropped into something else.

I tried to get away from disability issues and tried to build a career into something else. I think my dad would have been real happy if I'd finally gotten a college degree. He'd also be happy to know that we actually got married. We did get to go back there and live with him almost to the point where he died. It was an important time for both of us to learn about ourselves and learn about what we like about where we live, not just live some place by accident. And learn how important the kinds of work we do are to us. I think Om Devi affirmed her desire to do art no matter what.

I still thought that I could get away from disability issues, but I worked at Alpha One for a number of years. Om Devi and I had separated for a while, and we decided we wanted to get back together. Maine wasn't working for her health so we shopped around the country for almost a year, and finally we settled on Santa Fe.

One of the programs that was developing in Maine where I was at the independent living center was starting one of the first programs under the Technology Related Assistance Act for Individuals with Disabilities, which was "technology assistance is assistive technology is equipment," right? Making things that work for people. And like [laughs] you need a federal program to do this, right? It was a way to try to implement this and get information to people.

Every state had a different kind of program. At Alpha One after we brought these accessibility lawsuits, I got placed with the technology related assistance program there. As a result of that I learned about the program in New Mexico which was up and running, so when I went to New Mexico, I had a consulting job.

Reflections on the ADA

Cowan: Is that part of the ADA, the technology act that you were just referring to?

Dibner: No, not at all.

Cowan: It's completely separate?

Dibner: Yes. We kind of skipped over the ADA completely.

Cowan: Yes, we certainly did. [laughter]

Dibner: Yes, well, the ADA, with all its virtues--I really think the ADA is a great law. It follows on the heels of Section 504, which only affected programs that receive federal assistance. The ADA takes that same language, the exact same language in Section 504, and says, "Not just if you get federal assistance, but if you're a state or local government you have to avoid discrimination, prepare plans, remove barriers and integrate people with disabilities in your state and local government programs, not just in your federally funded programs."

Actually, New Mexico is one of the states that turned down federal money after Section 504 because they didn't want to have to comply with Section 504. But when the ADA came along [laughs] they couldn't get out of it.

The ADA also extended protections to people with disabilities in privately-owned businesses that don't have anything to do with federal funding and to employment rights with employers who have fifteen or more employees which may not have any federal money, either. So the ADA expanded vastly on Section 504. But by the time it came around in 1990, many states like Maine and California already had laws on the books --the white cane laws, those are called, which are in the civil code, usually.

In Maine it's called the Maine Human Rights Act. And we used it extensively in Maine to fight this miniature golf course battle. And they used it for the bus battle. So many states already had laws that protected these rights, but the ADA made it much more substantial and universal and established national codes, building standards, basically.

The other acts that have come along, like the assistive technology act, are different in a lot of ways. They deal with specialized areas. The ADA, for instance, doesn't cover housing unless it's federally funded or unless it's a program of a state or local government. And because a lot of housing wasn't covered at all, in 1988 there were the amendments to the Fair Housing Act. It was called the Fair Housing Amendments Act of 1988 where they expanded the Fair Housing Act to include language like Section 504's language. Housing was covered, so the ADA doesn't cover it.

The Air Carrier Access Act also protects people on airlines against discrimination, so the ADA doesn't cover it.

The Assistive Technology Act wasn't really a rights act as much as it was a "Let's get some technology out there into people's hands." Each state developed a program on how they were going to do that. In Maine it was a training program. We worked with the community colleges all around the state and we had a satellite television program in the community colleges so all around the state you could participate in these trainings all on the same day. And you could ask questions of the trainers who might be in Portland and you might be in Presque Isle.

Cowan: Interactive?

Dibner: Yes, interactive television. That was wonderful! I haven't done that anyplace else. But I was just one of the trainers, someone else was running the program.

##

Cowan: Eric, do you have anything further to say about your activities in Maine before you decided to leave Maine and go to Santa Fe?

Dibner: The big difference was that more rural and impoverished areas really don't have as much service as urban areas. That was a big difference.

Cowan: So you came then to Santa Fe as a consultant?

Dibner: Yes, in 1991. That was the deciding factor of moving. Santa Fe was one of the places we looked at or thought about so we met there to think about it harder. We decided it would work and the opportunity was there. I was actually offered as a job and then it turned out it was just going to be a consulting position that might work out into a job, but finally it was just a consulting position. And that was fine, it worked out quite well.

I worked at that organization which was actually a project in the Department of Rehabilitation, which is housed in the state capitol, Santa Fe, but it was a statewide effort. It was like the 504 project at DLRC where they were trying to bring information to people in the sticks, and do advocacy and training around the state on technology issues. I worked on some Medi-Cal issues, which I hadn't been very interested in before.

O. Dibner: Medicaid, there.

Dibner: Medicaid, right. Medicaid. Because there were no attendant service programs, to speak of in New Mexico. There was an independent living program, New Vistas, and it had several offices.

It was like Alpha One in that it was spread out. It had several offices. But it was kind of funky. I had been used to much more industrious kinds of independent living centers and more widespread activism. In New Mexico it was even more rural than Maine: the same one and a half million population as Maine spread out in an area three and a half times the size of Maine so there were hundreds of miles you could go through without seeing a town. And again, most of the population was concentrated in the cities of Albuquerque and the central Rio Grande corridor which included Santa Fe, Taos, and to the south, Las Cruces. And it had a lot of this rural stuff that Maine had but even to a greater degree. It's a third world country.

And it was also similar to Maine in this independent "Don't tread on me" attitude. In Maine, the independence concept was you take care of yourself. And in New Mexico it was, "We're cowboys here," or something along those lines. It's not so much independence in New Mexico as it was kind of a rowdiness, if you will, of, "You better take care of yourself." [laughs] So independent living programs were squashed down by the big heel of the cattle barons in a sense.

O. Dibner: I served on the board.

Dibner: Om Devi was on the board of New Vistas for a while. What assistive technology meant in the federal act is providing the services to get the technology, providing the technology itself, the equipment and the support services to keep it going, and learning how to use it. So it's not just that you get plopped down in a wheelchair that might fit or might not fit. It's got to fit, you've got to know how to use it, and pay for it, and get it repaired when you need to. So that's what the idea in the act was.

Differences between Maine, New Mexico, and Berkeley

Dibner: We were trying to implement a number of things through Rehab in terms of getting equipment, getting services in the state, in general, because there just weren't any in New Mexico. They were very few and far between. It was kind of an interesting effort. To me it was much more frustrating than any other place I'd worked so far. It didn't really work.

Cowan: It didn't.

Dibner: No.

Cowan: Why?

Dibner: There wasn't enough critical mass, partly. Critical mass--we haven't talked about it but it is something essential to make something happen. In New Mexico things were very spread out and people were very trampled down.

O. Dibner: There wasn't quite enough of an activist mentality. There weren't enough people with that idea--or if they did have it, they didn't know how to move forward with it. And the people that were in a position that, I mean, if they were directors of the independent living center they weren't activist leaders. They weren't interested in having loose cannons anywhere in the neighborhood, you know?

Dibner: It wasn't a movement at all. In Berkeley--obviously we came from a movement mentality right? But the time and the place and the people in New Mexico weren't right for real activism.

Cowan: Both people who needed the services and people who were providing the services--in neither case were they active enough. Is that what you're saying?

Dibner: Correct. Yes. The people providing the services came from very traditional models. New Mexico is a Spanish state. There are as many Spanish people as there are Anglo people. And there's maybe 10 percent that are Indian. The Spanish culture, the indigenous culture, a lot of the culture there is--maybe it's Mexican where this comes from, I'm not sure--there's a tradition of keeping people in back rooms. The word invalid is a real viable concept there. So there's a lot of much more old fashioned stuff going on there.

In Maine, despite the fact that we said you've got to fend for yourself to a certain degree there, the idea of independence goes back to the revolution--"We are struggling against the government." There is something to people being able to take care of themselves in Maine, which is a different kind of concept.

We're taking very stereotypical analyses of these two places, but I think that is something of the distinction. There's plenty of people in Maine who aren't getting out and doing anything, too. There's no transportation. The problem is if you don't live in a big town you can't get anyplace or do anything because unless mom or dad or brother or sister or your child is going to take you someplace, there is no transportation.

The ADA only requires transportation within a half-mile of a fixed-route system, a bus or a train. And beyond a half-mile you're not required under the ADA to provide any service.

Now, in most states there are rural transportation systems. In Maine around the cities, and the fairly settled areas, there is pretty good rural transportation--paratransit vans that are provided through the community service programs, not related to independent living programs. In New Mexico, those kinds of things really didn't exist hardly at all.

So without attendant services in a state, without transportation, you're in your own house and you don't get out to education, you don't get out to a job, and you may not get out of your house because there's no ramp there, either.

The other thing is if you need equipment or you need to get a wheelchair, you need to have a road to drive the wheelchair, a sidewalk. There are no sidewalks in New Mexico except in a few cities. I mean literally in New Mexico we lived on a street with no sidewalks. We lived in Santa Fe a few blocks from downtown, and there were no sidewalks. Some of

the town is 500 years old so some of the streets are very narrow.

And we were in the city! If you lived out in the country, you're talking gravel and dirt. And just having a wheelchair on a reservation doesn't make any sense, right? So these are the kinds of things the technology program was trying to deal with. But the community in New Mexico--there are people with disabilities who are organized. There wasn't a statewide organization as such that was a consumer organization, but people did get together around issues from time to time.

One woman, Linda Pedro, brought a suit because she couldn't get pay--there were some programs that would pay for some attendants under certain circumstances but not if they were family members. I think that was her lawsuit. She won that right just by bringing a lawsuit. Those kinds of individual acts were the way things changed.

There was another organization in New Mexico called the Governor's Committee on Concerns for the Handicapped [GCCH] which, like the Berkeley mayor's task force on people with disabilities, was a program set up to espouse the rights of people with disabilities. These governor's committees--there's one in every state. They come from the president's committee in Washington that sets the model. Most of them are called "for employment of persons with disabilities"--or they used to be called "for employment of the handicapped." Usually they're quite conservative and just work on putting up posters and talking, training some people about how industry can do better to employ people with disabilities.

In New Mexico the program, the Governor's Committee on Concerns of the Handicapped didn't focus on employment hardly at all. It was the real advocacy organization in New Mexico. There's some very strong personalities involved with it to the extent that it was kind of a private power base. The director, Judy Myers, is an excellent spokesperson for the rights of people with disabilities and has been involved in national issues for the rights of people with disabilities but has a hard time working with a lot of people.

There is in New Mexico a tremendous effort to try to kill any effort of activism. There are a lot of conservative forces in New Mexico so Judy became very protective of the little corner that she worked out of. And I really liked working with her but it was kind of crazy-making at times, also, because she was so worried that people were going to take things away.

We fought the "good old boy" forces on building standards issues there. We were constantly fighting as we are in California and as we had to in Maine to a certain degree, to see the access laws enforced. I got involved in that from the beginning of when I was in New Mexico because I was interested in building codes.

I got to know the governor's committee that way and ended up working for the governor's committee on employment of the handicapped, reviewing plans for schools--we did all the school plans in the whole state, we reviewed them for access--and generally being an advocate for accessibility--doing training, working with architects.

There were only eight staff, I think. The major focus that Judy had was on accessibility and on building standards, so we had this big campaign to try to get better and better building standards in New Mexico. That was the big effort that we got involved in.

Environmental Illness: Broadening the Definition of Disability

Dibner: The other one that I got involved in was working with people who had environmental illness. In New Mexico there was a very strong movement of people with environmental illness, multiple chemical sensitivities. We set up an organization called the Healthy Housing Coalition to try to educate people about how to design their buildings and in particular their homes so that they would not continue to cause problems for people who did have environmental sensitivities or start new problems for people who might move into them. Because our construction techniques are now so deleterious to our environment, this was an important effort to prevent disability as well as help accommodate people in their homes who had environmental illness. So I really became much more familiar with that issue there than I had been previously.

As the disability movement's grown and changed, more and more people with disabilities--different kinds of disabilities --have gotten involved in it. In the beginning it was people who used wheelchairs or had other mobility impairments. Well, that's several groups right there, plus people who are blind. That was a coalition. And eventually people who were deaf got brought in at CIL kind of as an afterthought. Actually some people who are deaf don't see themselves as people with disabilities, they just have a different kind of communication.

O. Dibner: Dale Dahl was a bridge there.

Dibner: Dale was a wheelchair user who was deaf who manned deaf services. People who are deaf have been culturally separated by the language barrier so they're kind of satisfied to be separatists, sometimes. The culturally deaf are.

But there's always been this bringing in of other waves of disability. Now people with mental disabilities are very involved in the independent living movement. It is a strong coalition now. The ADA recognizes physical and mental disabilities of any kind that substantially impair major life activities.

Environmental illness, however, is not--they're in the beginning stages of the real battle to get recognition, too, and to change society. In a way we're actually killing people --not to say that people with spinal cord injury weren't killed in some ways, you know, in the past, but just to get recognition that this hidden disability has a reality base. We don't really know what the cause is in a lot of cases.

We worked with the legislature. The office of the governor's committee is right across the street from the legislature. Judy was a real activist in the legislature. She had a little trouble initially realizing how important environmental illness is, but I think her point of view more was that she should be sensitive to it--[laughs]--but that people aren't going to see this as a real thing, so it's going to hurt us to espouse it.

Cowan: Oh, I see what you mean.

Dibner: But she was very into the politics of things. Her whole life is the politics of things. We did get some assistance from the legislature, although they've kind of back-pedaled now. But the Healthy Housing Coalition has got a book out on healthy living, healthy housing. That is a growing movement in this country which is closely allied with disability issues.

Disability Compliance Coordinator for the City of Berkeley,
1996-

Cowan: So you're keeping track of what's going on in New Mexico even though you're here now?

Dibner: Yes. And why did we come here? [laughs] Well, because in New Mexico the salary at the governor's committee when I left in 1996 was \$28,000 and I'm making almost twice that now. I'm making \$50,000 now.

Of course, we thought the cost of living wasn't much more here. It probably isn't much more here--Santa Fe is a very expensive place to live. There's just no economy there. There's nothing but the state government and tourism. And there's no place to go, career-wise.

Now, here's an irony--another irony in my list of ironies. The job that I have at the city of Berkeley I found out about because Ken Stein, who has been working at DREDF, told me that the job existed. He and I both applied for it, with a number of others--a lot of people applied for this job at the city of Berkeley as disability compliance coordinator because Anne Steiner who had had the job for a while left the city. Ken and I became the finalists. He had told me about the job, and then I had to come and compete with him. We were old friends [wry laugh], and in the end I got the job. And he's been very grand about it, and we continue to work together.

But because it seemed like a better opportunity, I've come back to work in Berkeley. And we're still doing the same stuff. We're surveying the city's buildings, we're trying to remove the barriers that were identified fifteen, twenty years ago, and improve on the accessibility of city government.

The city programs are by and large accessible. A number of the people who worked at CIL and that I worked with on the housing committee now work at the city of Berkeley. And one of the city council, Dona Spring, also came through the Center for Independent Living. She's a woman with a disability.

The commission that I staff as secretary in my role as disability coordinator is the Commission on Disability, which grew out of the mayor's task force on people with disabilities. So now I'm slave to my own machine. [laughter]

Cowan: A circle. [laughs]

Dibner: Michael Pachovas, who was also chair of the mayor's task force of the disabled, sued the city of Berkeley because some of our facilities weren't accessible [laughs] before I got here.

Curb ramps that Hale and I designed years ago we're taking out now and putting in curb ramps which meet disability accessibility standards a lot better. There were no standards

when Hale was designing those ramps. For a person with a mobility impairment like use of a wheelchair to get in and out of the street, there's got to be a lowered curb or ramp near the corner. And at the same time people who are vision impaired use the curb as an identifier of where they are when they get to the corner. Hale's perspective was, well, we'll push the curb ramps off to the side a little bit to avoid confusing blind people.

But those ramps aren't in crosswalks, they're away from the crosswalk. Because of drainage structures, fire hydrants, poles, and meters, sometimes they're quite away from the corner. And that, now, is viewed as too much of a hazard. People now are complaining these ramps are way out of their path of travel. "I want to go in a straight line; don't make me deviate one bit." So there's been this constant struggle with curb ramps to be accessible for both blind people and for people who can't walk up a curb.

In California we've had a standard that there shall be a bump at the bottom of the ramp, which now is in violation of federal standards, so we're trying to figure out the best way to go between all these different codes and needs and make an environment that's accessible for everybody.

Cowan: Why a bump at the bottom of the ramp?

Dibner: So with your cane you can detect where you're changing to the street. But there are so many bumps in the pathway. The best thing is if we could design each corner so it was identifiable by the distinct slope of the ramp and the ramps were all the same, you could identify them. But the ramps aren't all in the same place. Some corners have two ramps, some have one. With some it's on the apex of the curve, some it's off to the side. So in California, we've put grooves in the ramps. Blind people don't know what the grooves mean at all, but it's required to put grooves in the ramps. It's supposed to tell you which way the street is going. [laughs]

Cowan: And some are very steep.

Dibner: Yes, and some are too steep. So we've just done an inventory again, as I did in Oakland a number of years ago, of what ramps need to be removed. And we're working on a contract right now to do 500 more ramps.

The city council is very generous and is setting aside about \$750,000--for access to buildings, sidewalks, and parks--

the next several years to try to get this job done. And then we'll see where we go from there.

The process of making its programs accessible is supposed to have happened under Section 504, way back in 1978 after the ruling. After the regs got passed, all our programs were supposed to be accessible to receive federal financial assistance. Well, maybe they were, maybe they weren't. Then in 1990 the ADA said the same thing all over again because we're a local government. And we still don't have a plan that says how we're going to remove all those barriers. We're still working on a curb ramp policy. I'm working on those things right now.

We're working on standards for how to make a construction site on the sidewalk where you put a barricade safe for people, so a blind person doesn't walk into a hole or a person who uses a wheelchair can cross the street. The commissioner on disability called me--or wrote me an email--this morning about Shattuck and Cedar. There's no way for her to go down the sidewalk because of the construction. So we're constantly trying to make our policies and our programs more accessible for people with disabilities and trying to live with the ADA's requirements, but we still haven't completed the job of just getting the basic access to all our facilities, getting all our policies in place to conform with these rules that have grown out of this whole movement.

When this is all completed--let's say in five years we have all the corners as accessible as can be and we have a model policy in Berkeley--I still think there are going to be people calling and saying, "That construction site is blocking my sidewalk." And then I hope that we'll have it well enough implemented that we'll be able to just call up the inspector and say, "Go out and fix that."

This afternoon we were doing customer service training in the public works department where I gave a little pitch about disability issues and how you communicate. How do you respond to a customer if they've got a speech impairment. People still need to learn about how to communicate with people who have some difference from them.

It's a constant process of educating ourselves and recognizing our obligation to serve the customer. It's really no different from what was going on thirty years ago when we were learning to serve the customer. It's the same practice that we're trying to bring--not just to one individual now, but

to the--well, I don't want to say to the whole of society, but to the municipal government.

Final Thoughts

Cowan: Eric, do you have any final thoughts on our interview and your experience over these last years?

Dibner: Well, the thing I was going to say is that the more things change the more they seem the same, but there has been progress.

When I was at CIL, on the heels of Ray Lifchez's work, trying to develop models for integrating people with disabilities into the design process, Irving Zola came to CIL to see what was going on. He was a man like Itzhak Perlman, who had polio that he had learned to struggle with. You know, "I'm going to try to pass as a non-disabled person. He was a professor at Brandeis or someplace, and he went to Holland to study housing models. In Holland they had a project, Het Dorp The Village, which was this whole village set up for the handicapped. It was a totally different model from what we're working on here. It was a place where everything was provided for the handicapped. When he got there he was treated like a resident, and he realized, "My god, I'm disabled too." He was dealing with his own issues by trying to pass, but also seeing this place that had been created for those who could not pass, and "them" became "us."

Everybody was happy there but they could never cross the highway to get to where anyone else lived, so it was the opposite kind of test tube where everyone was put in together. And all the window dressing was there, but the people weren't recognized as people.

And in recognizing his own disability, he unleashed himself in a way. I can't remember the name of his book, but he wrote about the realization of your own disabledness. Now people talk a lot more freely about being disabled. People like John Hockenberry, who are fluent in the realm of success and ready to admit being disabled--admit that they have a disability and associate themselves with the disability movement.

And there are people like the guy who fell off his horse --Christopher Reeve--who are identifying themselves as disabled

people, but not identifying what it means to be a disabled person. For him the movement is to stop being disabled: "How can I cure disability?"

And although there's great virtue in trying to remove the physical impairment and the physical restraints that are on us by virtue of our health and congenital conditions, the idea of removing the disability as a negative thing, removing the personhood of people with disabilities, is not what the disability movement is about. It's about recognizing yourself and recognizing what your needs are. And a society recognizing itself and what it's made up of and changing to feel whole and complete with all its shortcomings.

So now, at the city of Berkeley, we have programs that are aiming toward integrating people with disability. We have staff people who still say things to me that I think are kind of backward about disability. Many people recognize much more what it means to be a person and to be a person who has a disability and recognize that the service we can provide as customer service people is the same we provide as a person assisting anyone.

Assisting a person with a disability is recognizing the need, listening to what the person needs, and responding to what you hear in an appropriate manner. That paradigm of help is something that the disability movement I think has taught all of society--that there's a ramp to be built every time you have a contact with someone. You have to remove your personal attitudes to a certain degree: bring your personality to the situation, with all the baggage, and try to make that communication or that service happen in a way so that baggage doesn't become a barrier.

We've started throwing off some of the trappings of our historic barriers, our historic institutional settings that we designed for people--the village of people with disabilities that can't communicate with anyone else--but we are still setting up those barriers every day. And it's not something that there is a final word about. It's something that we have to keep doing.

The housing situation in Berkeley is still almost the same as it was twenty-five years ago. There are still hardly any places to find that are accessible houses.

The attendant services situation is much better than it ever was.

The attitude about people with disabilities is much better because there are so many people on the streets, so many people who we have contact with. Medical technology lets us be in touch with people, plus people live longer. We recognize that those people are parts of our families and our businesses so it's a lot easier. The kids are in schools, now. It's a lot easier to see people every day.

But there's so much of the societal force--we're talking about business forces and how the market really dictates a lot of things--the people can't just say we want it and suddenly the whole world becomes accessible. You've got to deal with budgets, you've got to deal with the social structure, and you've got to deal with competing demands--defense and other kinds of forces that take money away from people.

So the energies of society have adjusted a little bit in relationship to where they were twenty-five years ago, but in many states there are still people in institutions. The ADAPT¹ effort right now--the organization ADAPT, a nationwide advocacy organization, has as its focus getting people out of nursing homes. People are still being warehoused with no way to get out. Actually, this is something that I didn't mention that GCCH worked on in New Mexico, but people still don't have an option of getting out because there's no way to support themselves in the, so to speak, outside world.

I hope that the current crop of people who come on the scene as adults having disabilities don't think that all the problems are solved. Because it's real easy to fall back into the institutions that Scott never wanted to go and that many of us came from, which is the hospital or the nursing home, but also the deprivation and ignorance of human life. You know, progress goes by little increments. There was an upwelling when CIL and the disability movement made its first charge, and now there's been a diaspora of people around the country and around the world working on these issues.

You're going to a conference [Society for Disability Studies] tomorrow that will bring together people from around the world. And how many people will be there? If 500 people show up, they've all got to go out and speak to 20,000 to spread the word.

¹Americans with Disabilities for Accessible Public Transportation--now changed to Americans with Disabilities for Attendant Programs Today.

There's still plenty to be done, but I think a lot of strides and small steps have happened in the right direction.

Cowan: Well, thank you very much for the interview.

Dibner: Thank you. You're welcome.

~

Transcriber: Amelia Archer
Final Typist: Jessica Lage

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III

Hale Zukas

NATIONAL DISABILITY ACTIVIST:
ARCHITECTURAL AND TRANSIT ACCESSIBILITY, PERSONAL ASSISTANCE SERVICES

An Interview Conducted by
Sharon Bonney
in
1997 and 1998



Hale Zukas, 1999.

TABLE OF CONTENTS--Hale Zukas

	INTERVIEW HISTORY	94
	BIOGRAPHICAL INFORMATION	95
I	EARLY YEARS THROUGH COLLEGE	96
	Relationship with Family and School Experiences	96
	Admission to the University of California, Berkeley, 1966	106
	Activities While a Student	109
	Getting a Power Wheelchair, 1971	114
II	INVOLVEMENT WITH THE CENTER FOR INDEPENDENT LIVING	118
	Establishment of CIL, 1971-1972	118
	In-Home Supportive Services History	123
	Community Affairs Coordinator for CIL: Picket Lines and Curb Cuts	135
III	504 SIT-IN, ARCHITECTURAL AND TRANSPORTATION BARRIERS COMPLIANCE BOARD, AND SEVERAL STUDIES	143
	Participation in the 504 Protests, San Francisco and Washington	143
	Moving Into Own Apartment, 1974	156
	Membership on Federal Architectural and Transportation Barriers Compliance Board, 1980-1983	158
	Urban Institute National Study	168
	Working to Make Bay Area Rapid Transit Accessible, 1975-1977	170
IV	PURSUIT OF PERSONAL INTERESTS, POWER AS A LEADER, AND VARIOUS OBSERVATIONS	173
	Discussion of Ed Roberts	173
	Future Issues in Independent Living	176
	Personal Observations	178
	More on Early Teachers	179
	Love of Trains and Bridges	181
	Parents' Expectations	185
	Views of the Ideal Job	186
	Burning Draft Card	188
	Power as a Disability Rights Leader	189
	Mobility: A Learned Skill	193
	Discussion of Alternative Living Options	194
	Example of Need to Continue Educating the Public	195

INTERVIEW HISTORY--Hale Zukas

Hale Zukas is a highly respected disability rights leader who helped shape the independent living movement and who learned to live independently because of the movement. He is a founding member of the Center for Independent Living; a recognized expert on Social Security, architectural barriers, and transportation issues on the national level; and a leader in attendant care support on the state level. His oral history paints a picture of a child with severe cerebral palsy growing up in the 1940s and 1950s, the barriers which had to be overcome, and the power he has developed as an adult leader.

A native Californian, Mr. Zukas talks about his parents' refusal to consider institutionalization, an alternative considered for him by the medical profession; about his early years in a one-room school, in residential school settings, and his fight to enter a non-segregated high school. Even his admission to the University of California at Berkeley in 1966 was not easy. He describes life without a wheelchair and getting around in his family home and in school, daily exercise and therapy routines, learning to type, and interactions with parents and siblings--all of which contributed to the person he is today.

Hale Zukas is a founder and early staff member of the Center for Independent Living. His early work with the city of Berkeley promoted curb cuts around the University of California at Berkeley campus so that students had easy access to the immediate campus surroundings and eventually to all of Berkeley. His advocacy with the state legislature helped establish In-Home Supportive Services and led to his being able to move out of the family home and into his own apartment to live independently in 1974. His ongoing analysis and advocacy at the state level for over twenty-five years has shaped California's personal assistance program. In addition, he is a well-known activist in a myriad of progressive causes in the Bay Area.

Mr. Zukas was a participant in the 504 sit-in in San Francisco in 1977 and went to Washington to lobby for the signing of the HEW regulations for Section 504 of the 1973 Rehabilitation Act. He has been active in influencing local, state, and national transit policy. He spearheaded efforts to force Alameda-Contra Costa Transit to adopt and implement a policy of accessibility in the late seventies. His work with the Bay Area Rapid Transit Study, and his continued current efforts with BART, have led to a transit system which gives mobility around the Bay Area to people with disabilities. On the national level, Hale has contributed to efforts to effect federal accessible transportation policy; in 1983 he became vice-chair of the Architectural and Transportation Barriers Compliance Board and greatly influenced national accessibility standards.

The interviews with Mr. Zukas were recorded from March 5, 1997, to May 28, 1997. After review of the transcripts two follow-up interviews were conducted in January 1998, for a total of twelve interview sessions. Mr. Zukas used a translator during the interviews who repeats what Mr. Zukas says. The translator's clarifying questions are audible in the interview, but not transcribed. The interviews were conducted in Hale's living room with tea and cookies usually served to the interviewer. On a couple of occasions, Hale's mother was in the room or an attendant was working in the kitchen and can be heard in the background.

The taped interviews were transcribed, very lightly edited by the interviewer, and sent to Mr. Zukas for his review. He made no substantive changes. On March 12, 1998, a one-hour videotaped interview with Mr. Zukas was recorded. The video- and audiotapes are available for listening at The Bancroft Library. Mr. Zukas has placed his personal papers relating to his work in the disability rights movement in the Disabled Persons' Independence Movement collection at The Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sharon Bonney
Interviewer/Editor

August 17, 1998
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Hale Joseph Zukas

Date of birth 5-31-1943 Birthplace Los Angeles

Father's full name Bronislaus Joseph Zukas

Occupation Teacher Birthplace Brooklyn, N.Y.

Mother's full name Helen Margaret Hale Zukas

Occupation Teacher Birthplace Tnyo County, CA

Your spouse _____

Occupation _____ Birthplace _____

Your children _____

Where did you grow up? Mostly San Luis Obispo

Present community Berkeley

Education B.A. in Mathematics, U.C. Berkeley

Occupation(s) Community Advocate and Policy Analyst

Areas of expertise Eliminating physical and social barriers to people with disabilities. Specific areas: transportation and architectural barriers and personal assistance services.

Other interests or activities Public affairs, politics, construction (highways, bridges), trains.

Organizations in which you are active World Institute on Disability, Metropolitan Transportation Commission, Public Authority, Elderly + Disabled Advisory Committee →

on In-Home Supportive Services in Alameda County,
Advisory Committees to AC Transit and BART,
Alameda County Transportation Authority Citizens Advisory Committee,
Berkeley Citizens Action, Regional Alliance for
Transit.

I EARLY YEARS THROUGH COLLEGE

Relationship with Family and School Experiences

[Interview 1: March 5, 1997] ##¹

Bonney: This is Sharon Bonney. I'm interviewing Hale Zukas today, and it is Wednesday, March 5, and I am in Hale's living room. We are also joined today by Nina Sprecher, who will translate for Hale.

Hale, I'd like to start out if I could by getting some family background. Can you tell me who your parents are, where they were born, that sort of thing?

Zukas: My father was born in Williamsburg, Brooklyn, New York, in 1912, and died a few weeks after his eightieth birthday. My mother was born near Bishop, California, in 1917, and moved to a ranch near Pixley when she was two years old. She now lives in Oakland.

Bonney: What did your father do for an occupation?

Zukas: He was a math teacher, mainly of junior high.

Bonney: And did your mom work? Other than being a mother and a homemaker?

Zukas: For about ten years, in the sixties and seventies, she was a substitute teacher in primary grades.

Bonney: When were you born, Hale? And where?

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

- Zukas: In 1943 in Los Angeles.
- Bonney: Have you lived in California all your life?
- Zukas: Yes, except for three years on Long Island, New York.
- Bonney: Tell me about your early childhood. After you were born, how long did you live in California? And then why did your family move to New York?
- Zukas: We lived in Los Angeles until 1948, when we moved to San Luis Obispo [California]. There were two primary reasons we moved. One was that California State Polytechnic College was there, where my father could continue his teacher education. One of the first--if not the first--schools for disabled children was there. [points to picture of himself and teacher in the school] I forgot I saw that teacher last week, and I meant to take the picture.
- Bonney: What school was that, Hale? Was it a regular public school?
- Zukas: Chris Jespersen School. Chris Jespersen was a very powerful state senator, and one of his friends has a son with cerebral palsy.
- Bonney: Was it a school just for children with cerebral palsy?
- Zukas: At the beginning, I don't remember anyone who did not have CP.
- Bonney: And how old were you when you went there, when you started there?
- Zukas: Five.
- Bonney: And how long did you stay there?
- Zukas: Four years. And then I spent a couple of years at the Northern California Residential School for Cerebral Palsy.
- Bonney: Let's stick with the Chris Jespersen School first. Can you describe for me what a typical day was there for you?
- Zukas: In general, most of it was low-level academic work. I had periods of physical and speech therapy during some of that period.
- Bonney: Were you going through the school, Hale, like kindergarten, first grade, second grade? How was it set up?
- Zukas: They didn't have--it was essentially a one-room school.

Bonney: And how many children were there?

Zukas: I believe ten or fifteen.

Bonney: How did the decision get made to send you to this school? What were the dynamics about that?

Zukas: You would have to ask my mother. You're talking about Chris Jespersen School?

Bonney: Yes. How did you feel about being in school there?

Zukas: I think I liked it.

Bonney: Why did you like it?

Zukas: Well, I guess it was something different. I don't have a good answer.

Bonney: What was your childhood like up until you went to this school? Were you sheltered mostly at home? Did you have young friends? What was your life like?

Zukas: I don't remember having any childhood friends.

Bonney: Do you have brothers and sisters?

Zukas: Yes. My sister was born a few months before we moved to San Luis Obispo, and my brother was born a year after.

Bonney: What was your relationship like with them?

Zukas: I keep thinking you should ask my mother. My sister was more resentful than my brother. One thing I do remember is that my mother drove me to do exercises.

Bonney: At home? Did she do therapy with you? Tell me a little bit about that.

Zukas: She made me do much more than I wanted, and I think that has shaped my persona ever since, both for good and ill.

Bonney: What was the good?

Zukas: That I have accomplished so much and been so active.

Bonney: And what do you think was the bad?

Zukas: That I have very low self-esteem.

Bonney: And why did that develop out of the therapy sessions?

Zukas: Being forced to do so much that I didn't want to do.

Bonney: What were your parents' attitudes towards your disability?

Zukas: My mother definitely took a leading role and pushed to open doors for me. Last week at one of my relatives', someone remarked--

##

Zukas: Someone remarked about how my father took the kids to the library every week, and that included me. But my general impression is that Bronney [father, Bronislaus Zukas] went along with what Helen, my mother, wanted--sometimes not too happily.

Bonney: Did your father ever talk to you about your disability?

Zukas: Not that I remember.

Bonney: Did he push you in any way to do things or go to school or encourage you to have a life?

Zukas: Well, that's hard to say. He did take me a lot of places.

Bonney: It was very common in the forties or fifties frequently for children who had disabilities to be institutionalized--taken out of the family. Was there ever any talk about that with you?

Zukas: Yes. Helen has said that in my very early childhood she would see me doing more and more. Then she would go to a doctor who would talk about how mentally retarded I was and that I should be in an institution. And her spirit would plummet. And then the cycle would repeat itself.

Bonney: So the cycle kept going over and over again with the doctor. How did it come about that you never were institutionalized? What happened?

Zukas: I left something out. She finally decided that she knew more than the doctors.

Bonney: So your parents made the decision not to go along with it.

Zukas: Yes.

Bonney: Did you come from a religious family, Hale?

Zukas: No. My parents were both leftists. My mother's parents and many of her brothers and sisters were religious.

Bonney: You said that when the doctors would tell your mother that you were retarded and should be in an institution, her spirits would plummet. What did she lean on to bring herself back up?

Zukas: Her observations.

Bonney: Of what you were capable of doing. Was your family rich?

Zukas: Hardly.

Bonney: And what about yourself? Are you a religious person at all?

Zukas: No.

Bonney: And what's your political affiliation? They were leftists; what are you?

Zukas: Leftist, although there are times when I feel and am regarded as a conservative in a given context, and that makes me uncomfortable.

Bonney: You don't want to be labeled a conservative?

Zukas: No.

Bonney: Are you a conservative in some contexts?

Zukas: Yes.

Bonney: So what makes you uncomfortable about the label?

Zukas: I regard being a conservative as bad.

Bonney: Let's go back a little bit into your childhood again. You said that when you were in the Jespersen school that it was low academic work. Did you realize as a child when you were in that school that you probably weren't being challenged?

Zukas: I don't know. When it came time for me to leave the residential school, people had decided that the only way I was going to make anything of myself was with my head, that I wasn't going to get anywhere along those lines if I went back to Chris Jespersen. Let me back up. In my two years at the residential school, the main goal eventually became finding a

way for me to communicate. In May, one Saturday I was waiting for my parents to pick me up to take me home for a break, when the occupational therapist came and said, "Maybe you can type with your feet." So I went to OT [occupational therapy] and they put a dowel on my foot, and for the first time I typed my name. In the meantime, my parents came while I was at the typewriter. At some point, they told me that Helen's sister, who had taken the most interest in me, had died in a car wreck. I will always think of that as one of the most ironic moments of my life.

Anyway, during the next several months my typing improved, but there were a lot of problems with typing with my feet. So about a week before I was to go home for good, OT got the idea of using my head.

Bonney: Hale, let me ask you: how old were you when you typed your name for the first time?

Zukas: Not quite eleven.

Bonney: And up until that time, how did you communicate? Did you talk like you are now, and were people translating for you or what?

Zukas: When they brought me to the school the first day and were about to leave, I said--

##

Zukas: When they first brought me to the school the first day, I said, "Tell them how to understand me." And they said, "We can't."

Bonney: But your parents understood you. You could communicate with them?

Zukas: Yes.

Bonney: And your brother and sister too?

Zukas: Yes. Thinking back on those few months, what sticks in my mind is not problems arising from people's inability to understand me, but my being able to dictate letters home to one certain attendant, so communication must not have been as much of a problem as I had feared.

Bonney: What were your parents' reactions when they came in to the school and found that you had typed your name?

Zukas: I don't remember.

Bonney: What was your reaction?

Zukas: I was happy, of course.

Bonney: Did it liberate you?

Zukas: Yes. There was one attendant at the school who was particularly good at taking dictation. During the next ten or so years, I would spend hours writing Christmas cards, and I never write Christmas cards anymore. [laughter] I never type anymore even though I'm much faster than I was then. The decline in my industriousness has been depressing.

Bonney: Why are you less industrious?

Zukas: I guess I've just become more lazy, and maybe my disability has become more of a burden over the years.

Bonney: Hale, I want to go back. When you were in the rehab center-- that was the residential school? You called it a rehab center earlier?

Zukas: No, I didn't. The residential school was in Redwood City [California].

Bonney: Okay. When you were there, which is where you learned to type, when you first went there did they consider you retarded?

Zukas: I don't think so.

Bonney: What I'm getting to is I'm curious that you had been then taught to read and write?

Zukas: Yes.

Bonney: Okay. So you got an education there.

Zukas: Another thing that my father did is read to us.

Bonney: And of course you understood all that.

Zukas: Yes.

Bonney: Now, you left the residential school when you were eleven, or thereabouts?

Zukas: Yes. They sent me home early because they had to move to a new building behind Stonestown.

Bonney: Oh, the shopping center?

Zukas: Near San Francisco State [University].

Bonney: When you went home at eleven, what was life like then? Did you go to school someplace?

Zukas: My father was teaching seventh grade in Arroyo Grande, and by that time we had moved to an old Victorian about a mile from Arroyo Grande. Are you aware of the county displays on the first floor of the Capitol?

Bonney: No.

Zukas: Well, anyway, each county has a three-by-four foot display, and for many years there was a picture of the place where we lived.

Bonney: Oh, the Victorian.

Zukas: Which was on the second floor. But my room was the tower.
[laughter]

Bonney: I assume you couldn't even get into the house from outside. Was it ramped?

Zukas: No.

Bonney: How did you get in and out and get up to your bedroom?

Zukas: People would hold me from behind and we would climb, and Helen would insist on my doing it right.

Bonney: [laughter] Which meant what?

Zukas: Taking my own weight.

Bonney: Did you have a wheelchair at this time?

Zukas: When I went to the residential school I had two means of getting around. One was a wooden chair which Helen made in an adult education class.

Bonney: Was it a chair with wheels or was it a chair that you pushed along?

Zukas: It had small casters.

Bonney: And did you sit in it and push with your feet? Is that how you got around?

Zukas: People pushed. I also had a walker which my machinist uncle made.

Bonney: And at what point in life did you get a wheelchair?

Zukas: When I left the residential school, I had learned that I could kick the spokes of a wheelchair with the big wheels in front.

Bonney: So when you were eleven then, you got this wheelchair with the big wheel in front which you kicked with your foot. And you used that in the Victorian house?

Zukas: No. I think it was left at school. People walked me around the house anyway. As I said, people figured I wouldn't make much of myself at Chris Jespersen School. So they negotiated to get me into the school where Bronney taught.

Bonney: So you went to an integrated school system.

Zukas: Yes.

Bonney: Were you in an integrated setting then from age eleven on through high school?

Zukas: I spent a year and a half in seventh grade. At the end of the second year, Bronney left because he had had it with teaching. Helen negotiated with the school to get them to let me into the eighth grade. The second school in the district had just opened, and it was named for one of the eighth grade teachers, which gives you some idea of how old the teachers were. [laughter] Anyway, neither of the eighth grade teachers would accept me, and I remember Helen and me crying after the final session. So I studied at home that year. We negotiated with the high school to let me in.

##

Bonney: So you negotiated to go into high school.

Zukas: We had that arranged, then our landlord sold the house and we had to move. So we moved back to San Luis Obispo. We moved back in the city for the first time in nine years. So we had to start all over negotiating. One time the assistant principal of the junior high came over with one of the social studies teachers. I was extraordinarily tense, and I was a frightful sight. The assistant principal was obviously horrified, but the social studies teacher wasn't spooked. So I started, and I finished the ninth grade and went for two and a half years of high school, taking three classes a year.

Bonney: And you went to the school every day? You were integrated into the classroom?

Zukas: Yes.

Bonney: And how did you like that? How did you feel about that?

Zukas: Pretty good.

Bonney: Were you accepted by the other students?

Zukas: At least some of them.

Bonney: Would it have helped, Hale, when you were going through this if you would have had the Education for All Handicapped Children Act in place?

Zukas: Yes.

Bonney: Did you ultimately have anything to do with passage of that law?

Zukas: No.

Bonney: But it certainly would have helped.

Zukas: Yes. In the summer of '59 Bronney suddenly announced he was moving back to New York. In February or March of '60 we drove back. He arranged for me to go to the local high school. During a little more than three years we lived in four houses. It was decided that Helen and the children would come back to California in the summer of '63, and someone noticed that I would be only one class short of graduating from high school, and I added another class. So I graduated.

Bonney: When you were in New York, in school, did you know Judy Heumann?

Zukas: No.

Bonney: You didn't cross paths with her then. You and your mom and brother and sister then came back out to California after you had graduated?

Zukas: Yes.

Bonney: Did you move then to the Berkeley area? Is that when you came to Berkeley?

Zukas: Over on Woolsey Street.

Admission to the University of California, Berkeley, 1966

[Interview 2: March 19, 1997] ##

Bonney: This is Sharon Bonney, and I'm interviewing Hale Zukas today. It's Wednesday, March 19. Nina Sprecher is joining us as translator, and we are in Hale's living room.

We were talking up to this point, Hale, about your childhood years and your growing up years. We're up to the point now where you have just returned to the city of Berkeley, and you had just graduated from high school. Can you tell me how you got to college?

Zukas: Well, actually, last night I realized that I don't remember what I did between summer of '63 and summer of '64.

Anyway, we knew that it would take some doing to get me admitted to UC. So in the fall of '64 I enrolled in a beginning calculus course through UC Extension. I took the first and second semesters. Remember the Free Speech Movement was during the fall of '64. The class was in Dwinelle Hall. I can remember one night hearing Joan Baez in Sproul Plaza.

Bonney: Was she part of a demonstration, do you mean?

Zukas: Yes.

Bonney: And this is the time when you were taking just the one course through the extension, right?

Zukas: Yes.

Bonney: But you were on the Berkeley campus participating in the Free Speech Movement.

Zukas: No. At the calculus class in Dwinelle Hall.

Bonney: Oh, okay.

Zukas: We also had to get the Department of Rehab [Rehabilitation] to agree to support my education.

Bonney: How did you do that, Hale?

Zukas: Oh, yes, before I get to that--in early '65 I wrote a letter to UC inquiring about getting admitted. And Arleigh Williams wrote and said they couldn't admit me because I couldn't meet the foreign language requirement.

Bonney: The spoken word?

Zukas: Yes.

Bonney: And how did you counter that argument?

Zukas: I wrote a letter to some of my high school teachers asking them to write the vocational rehab counselor about their knowledge of me and to send copies of their letters to UC. One of my English teachers in New York didn't get it straight, and he wrote directly to UC an embarrassingly laudatory letter. The dean of admissions, F. T. Malm, called and came over to meet with us. They decided I could take a correspondence course in Russian and fulfill the foreign language requirement that way.

Bonney: Did you do that?

Zukas: Yes. I entered UC in the spring of 1966.

Bonney: Were you required to complete the Russian course before you were allowed to enroll at UC? Was that a condition, that you had to pass Russian to be able to get in?

Zukas: Yes.

Bonney: How did that make you feel?

Zukas: I think I felt it was kind of ridiculous that they held on to the foreign language requirement, but at least they were willing to modify it enough so I could fulfill it.

Bonney: Did you take just the one Russian course, Hale, or did you take more than that?

Zukas: Oh, a lot more--before and after I entered.

Bonney: I understand that at some point you worked as a Russian translator? Is that correct?

Zukas: How did you know that?

Bonney: I think Eric Dibner told me that. I think that's how I heard it. That's why I wondered if you took more than just one

Russian course. You seem to know Russian quite well if you could do that.

Zukas: Well, yes. In the fall of '71 I did translate one article for the Joint Publications Research Service, which was a government agency, and then they let me go. Later, I ordered a copy of the article and it was my translation. So we speculated that my subversive past did me in.

Bonney: Did you want to be a translator?

Zukas: Yes.

Bonney: After college that was the career you were going towards at that point?

Zukas: Yes, at that point.

Bonney: Did you do anything about being let go? Did you talk to anyone or ask any questions?

Zukas: No.

Bonney: What reasons did they give you for letting you go?

Zukas: As I remember, they didn't give any.

Bonney: So let's go back to how you got into Berkeley and when you got into Cal. You came in the spring of '66, I believe you said. Tell me where you lived and how you ultimately got in.

Zukas: By this time, DR [Department of Rehabilitation] had taken me on. They bought me a Selectric typewriter.

Bonney: Who was your counselor?

Zukas: Catherine Butcher.

##

Bonney: When you went to UC Berkeley, did you go into the residence program--the Cowell Hospital program?

Zukas: No.

Bonney: So where did you live?

Zukas: On Woolsey Street, a little more than a block up from Shattuck [Avenue].

Bonney: Were you living at home and going to school?

Zukas: Yes.

Bonney: What major did you go for?

Zukas: Math.

Bonney: Is that what you got your degree in?

Zukas: Yes.

Bonney: And I heard that you graduated with honors or distinction?

Zukas: With distinction.

Bonney: How did that make you feel?

Zukas: Good.

Bonney: Did it change anybody's mind or opinions about people with disabilities?

Zukas: I wouldn't be surprised. I just found out that Matthew Wangeman has been accepted into the Ph.D. program in the School of Public Policy.

Bonney: Do you feel you're a role model for Matt?

Zukas: No. Well, perhaps.

Bonney: When you got into Cal, when you started going to school, you went from '66 to--I think you graduated in '71?

Zukas: Yes.

Bonney: So it appears that you pretty much took a full courseload every semester? Tell me about what your workload was like.

Zukas: In the fall of '66, UC switched to the quarter system and I usually took two courses a quarter.

Activities While a Student

Bonney: When you were in college, what activities did you participate in? You said you lost your translator job because of your past

activities, so it must have been during this time period. What were you doing as a Cal student?

Zukas: Well, what may have cost me that job was my turning in my draft card to be burned.

Bonney: The U.S. government sent you a draft card? [laughter]

Zukas: I was in New York when I turned eighteen, so that's where my draft board was. I was classified 4-F, but after I turned in my draft card they reclassified me 1-A. [laughter]

Bonney: Now 4-F meant what?

Zukas: Disqualified for physical reasons.

Bonney: So did you ever get drafted?

Zukas: Yes. I wanted to go, but I needed to have my induction moved out here from New York. And in order to do that, I needed to go into the local draft board.

Bonney: So did you do that? Did you go to the local draft board?

Zukas: Yes.

Bonney: And what happened then?

Zukas: They quickly canceled.

Bonney: [laughter] Did they think it was humorous?

Zukas: Not that I recall. [laughter]

Bonney: Okay. So you burned your draft card. Were you ever a member of the Rolling Quads?

Zukas: No.

Bonney: While you were in school were you friends with John Hessler?

Zukas: I became acquainted with him through PDSP [Physically Disabled Students' Program].

Bonney: What were your interactions with John?

Zukas: What do you mean?

Bonney: At that point was he the director of PDSP?

Zukas: Yes.

Bonney: Did you work with him at PDSP on projects together?

Zukas: They asked me to join the advisory board.

Bonney: What kind of things were they doing on the board at the time?

Zukas: I don't remember much except being involved with the renewal proposal for PDSP.

Bonney: Did you help write the renewal?

Zukas: I don't think so. There was a proposal for setting up a house where disabled students would live.

Bonney: Was this part of the attempt of the students to move out of Cowell Hospital and into a different kind of residence program?

Zukas: Yes.

Bonney: Okay, so it was that proposal. Did you work on that?

Zukas: Yes.

Bonney: What did you do?

Zukas: I guess I contributed ideas.

Bonney: What did you see John Hessler doing as part of this project proposal? Where did he stand?

Zukas: I think he was supportive.

Bonney: Of finding a home.

Zukas: Yes.

Bonney: Were there other people who wanted some other kind of arrangements?

Zukas: Not that I recall.

Bonney: Because ultimately they ended up in the residence hall in Unit II. Do you have any recollection of how that came about?

Zukas: Do you remember when that was?

Bonney: It must have been around '71 or '72.

Zukas: When I had become much less involved with PDSP.

Bonney: Back in your college years, did you have any interactions with Ed Roberts as a student?

Zukas: No.

Bonney: Not as a student. Later on at CIL?

Zukas: Yes.

Bonney: And how about Judy Heumann? Did you see her as a student?

Zukas: No. She came out here in '73, '74, or '75. Anyway, long after I had graduated.

Bonney: What other activities did you take part in as a student at Cal?

Zukas: I would go to a few political meetings.

Bonney: What kind of meetings?

Zukas: Various leftist groups. I went to meetings of the Scheer campaign.

Bonney: Robert Scheer? What office did he run for?

Zukas: Congress, in 1966.

Bonney: Did he win?

Zukas: No, but he came surprisingly close to defeating the incumbent mainstream liberal.

Bonney: What was that person's name?

Zukas: Jefferey Cohelan.

Bonney: Is that Robert Scheer of Ramparts magazine?

Zukas: And now the Los Angeles Times.

Bonney: What with the L.A. Times?

Zukas: Robert Scheer is now a writer with the L.A. Times. Anyway, in '68 John George ran against Cohelen.

##

- Bonney: We were talking about John George running against Jefferey Cohelan. What happened then, Hale?
- Zukas: In '70, Ron Dellums ran and beat him. Thanks to [President] Richard Nixon.
- Bonney: Let me clarify then: Ron Dellums beat Jefferey Cohelan thanks to Richard Nixon?
- Zukas: Yes.
- Bonney: And how did John George fit in there?
- Zukas: He ran in '68 but didn't beat him.
- Bonney: Okay. I want to go back a little bit. When you were a student at Cal, what kind of services did you get at PDSP?
- Zukas: My recollection is that PDSP was established at the beginning of the '70-'71 school year. Well, that was my last year.
- Bonney: How did you survive as a student? What did you do to get through your coursework? Did you hire your own people to help you?
- Zukas: I would ask for volunteers to make copies of their notes and to push me from class to class.
- Bonney: And how did you take tests?
- Zukas: I would take them home and do them on the typewriter.
- Bonney: Did you go through graduation ceremonies?
- Zukas: No. When I said "thanks to Nixon," I was alluding to the invasion of Cambodia, which happened in the spring of '70. And the whole campus was in an uproar. The regular graduation was obviously not held, and for some years graduations were held by the various departments. I don't remember why I was not part of it.
- Bonney: Now a number of years ago--I think around 1990 or '91--those classes that didn't have a graduation got together through the Alumni Association and did have a graduation reunion. Did you participate in that?
- Zukas: No.

Getting a Power Wheelchair, 1971

- Bonney: You had some other things you wanted to mention about this time period, Hale.
- Zukas: During my whole time at UC, I was in a push chair. It was only after I started hanging around PDSP that people, and Herb Willsmore in particular, began pushing me to try an electric wheelchair. And I didn't think I could do it. But Herb kept pushing, and so I tried. I found it was pretty nice. First, I tried out one of those old E&Js. Then I tried out Phil Draper's chair, and for a few months I would use his chair once a week while he had his bowel program.
- Bonney: Did you live together?
- Zukas: No.
- Bonney: How did you work these chairs the first time? The chair you're in now you operate with your headstick. I'm assuming that you didn't have the headstick at that point?
- Zukas: Remember I got my headstick in '54.
- Bonney: Okay. Then how did you drive the wheelchairs? Did they have the gizmo on it where you could stick your headstick in it or did you have to push that tiny little joystick?
- Zukas: First they put a funnel on.
- Bonney: Who was "they," Hale?
- Zukas: People at PDSP.
- Bonney: Is this Chuck Grimes?
- Zukas: Yes.
- Bonney: So how did it come about that you got your own chair?
- Zukas: We got it authorized by Medi-Cal.
- Bonney: Did DR help you buy the chair?
- Zukas: I don't think so. One time, the Medi-Cal consultant called to ask some questions, and Helen said somebody would be along with me all the time, and I got very upset.

Bonney: So your mother said that someone would be with you all the time, and you got very upset because--

Zukas: I figured that eliminated one of the main reasons for getting it.

Bonney: So what was your mother saying? That you did not need a power chair because someone would always be with you to push you? Was that the issue?

Zukas: I think she was saying that I wouldn't be out on my own.

Bonney: And she was saying this to the Medi-Cal person, who was perhaps going to buy the chair for you. Did that statement jeopardize the wheelchair?

Zukas: Apparently not.

Bonney: Okay. But it made you angry with your mom.

Zukas: Yes.

Bonney: Did you have a talk about that when the Medi-Cal person left?

Zukas: Yes.

Bonney: Tell me about that.

Zukas: Actually, I figured I would be out on my own and that she shouldn't have said that someone would be with me all the time. I told her I had planned I would be by myself and that she shouldn't have said somebody would be with me.

Bonney: So this was really a crisis time for your mother.

Zukas: What do you mean a crisis?

Bonney: Was this a time when she had to realize that you were going to be more independent than you had ever been before, and that you would go off on your own and do things? And perhaps this had never occurred to her before that you would do that? Was this a time of her having--

##

Zukas: First, I should say I have no direct memory of it. I only remember her mentioning it. I think she probably took it pretty matter-of-fact.

Bonney: So when you got your power chair you were off and running and you went on your own.

Zukas: Yes.

Bonney: How did it feel the first time you got in your own chair and went somewhere?

Zukas: Great. But the first time I went out on my own, I was by the Smokehouse at Woolsey and Telegraph when one of the motors stopped working, and I didn't have my board. But who should come along but Chuck Grimes!

Bonney: Always in the right place at the right time. [laughs] That's wonderful. So what happened when Chuck came along?

Zukas: He saw that one of the motors was unplugged.

Bonney: Oh.

I wanted to ask a follow-up with DR. So DR never did buy your wheelchair; it was Medi-Cal that bought it. Is that right?

Zukas: Yes.

Bonney: Okay. Did DR fund anything for you going through college other than tuition? I assume they funded tuition?

Zukas: Yes, and they also paid for my transportation and books.

Bonney: To and from campus? What was the transportation?

Zukas: I would ride in a taxi. And then after a while Tim, my brother, would push me home.

Bonney: Are there things you want to say about this time period?

Zukas: That I got my power chair in December of '71.

Bonney: How old were you, Hale, when you got your chair?

Zukas: Twenty-eight.

Bonney: Okay. What else?

Zukas: Nothing.

Bonney: Nothing about your college years and up through CIL?

Zukas: No.

Bonney: When did you get your van? Later? Do you want to talk about that now?

Zukas: No.

II INVOLVEMENT WITH THE CENTER FOR INDEPENDENT LIVING

Establishment of CIL, 1971-1972

[Interview 3: April 9, 1997] ##

Bonney: Today we want to talk, Hale, about your CIL days. Let's talk about when you first went to CIL. How did you happen to end up there? What was the occasion for you to go there the first time?

Zukas: What do you mean "when I first went to CIL"?

Bonney: Was CIL already formed when you went there or did you help form it? And if so--

Zukas: Hell, no.

Bonney: What were the circumstances around your first interaction with CIL?

Zukas: Aren't you aware I was there from the beginning?

By early '71 it was apparent to PDSP that students were not the only ones coming to them for services. The people in the community were coming there for things like wheelchair repair and attendant referral. While PDSP would usually serve them, they knew that the mission of PDSP was to serve students. So in May of '71, Mike Fuss invited me to a meeting on May 17 to see about establishing an organization which would provide similar services to PDSP's to people in the community.

Bonney: And what happened at that May meeting? Who was there?

Zukas: I think Herb Willsmore, Judy Taylor, Larry Langdon, and I presume John Hessler and Mike Fuss.

Bonney: Was Ed Roberts there?

Zukas: No. I have always had problems of Ed being called a co-founder of CIL because as I recall, he did not become involved until a few years later.

Bonney: So who do you think are the founders of CIL?

Zukas: The people who were involved during that first year, when it was a desk at PDSP. I should say I don't actually remember that meeting on May 17. I am more or less inferring who was there, and I should add Phil Draper and Jan [McEwen].

Bonney: Do you think this group of people then are the founders of CIL?

Zukas: Yes.

Bonney: I never knew that CIL started as a desk at PDSP. How did it grow from there?

Zukas: CIL didn't get its first real money until July of '72.

Bonney: And was that money from the city of Berkeley? Was that the first money?

Zukas: No. From the Rehabilitation Services Administration.

Bonney: From Washington? Federal money?

Zukas: Through the regional office.

Bonney: Was that a grant proposal that money was given for? What kind of money was that? For a specific project or what?

Zukas: I think it was a planning grant. Anyway, in the first year we worked with what little money we had raised through things like card games. We had very little money.

Bonney: Were these card games like evening events that people came to play cards and give money to CIL or was CIL run off the winnings of the card games? [laughter] How did that work?

Zukas: I think the former.

Bonney: People came and paid to play cards and money went to CIL?

Zukas: Yes.

Bonney: Okay. So this was in '73 then, when you had some federal monies, and it was just starting. Is that the time frame? Or is this before the federal money?

Zukas: Before. After all, it took some time to get incorporated.

Bonney: So that's one of the things this group of people did? To incorporate CIL?

Zukas: Yes.

Bonney: Do you remember how much money the first grant was for?

Zukas: It was \$50,000.

Bonney: For a year?

Zukas: Yes.

Bonney: What did you all do with the \$50,000 that first year?

Zukas: For one thing, we rented an apartment in the building where Herb and Judy lived.

Bonney: Judy Heumann?

Zukas: No--

Bonney: Oh, Judy Taylor.

Zukas: Yes. I don't remember if John was still living there at that point or not.

Bonney: Judy and Herb lived in the apartment, and CIL was run out of the same building?

Zukas: Yes. I think there were about six or eight people being paid something out of that grant.

Bonney: What were the first services that you all started to establish?

Zukas: Financial benefits advocacy. During 1971-'72, we worked with the city of Berkeley to get a few more curb ramps, and I was put on staff because they were impressed with my work there.

Bonney: So you had been doing some of this before that time period then as a private individual?

Zukas: That was in the period when CIL was a desk at PDSP. There have been two times in my life--

##

Zukas: There have been two times in my life when I stayed up almost until dawn. One was working on a proposal to Tom Joe.

Bonney: Who was Tom Joe?

Zukas: I think he was somewhere in HEW, and he was to come out for a visit, which actually never came off. The reason I was laughing is that late yesterday afternoon I went into WID [World Institute on Disability] and Simi [Litvak] and Mary Ellen [Fortini] were sitting--[phone rings; tape interruption]

Bonney: So Mary Ellen and Simi were sitting--

Zukas: --shooting the breeze, and Simi said, "Did you ever think you would see us doing this on a day a proposal had to go out?" [to Sprecher] What happened earlier?

Sprecher: You're asking me what happened earlier?

Zukas: Yes.

Sprecher: Oh, well, Simi called here shortly before eleven, asking if you could come over and read the introduction that she had written and go over it. So I called down to L.A. to see if I could get the phone number of the meeting place where you were, and they couldn't, so I left a message.

Bonney: Now Hale, you said there were two times when you didn't go to bed until almost dawn. What was the second time?

Zukas: Watching one of my attendants taking the engine out of his van. That's another sad story.

Bonney: I think we'll leave that one for later. There's a rumor that goes around that you and Eric Dibner, sometime during this time period, used to go out late at night and lay asphalt down for curb ramps around the city of Berkeley. Can you tell me about that? Did you in fact go out in the dark of night and do that?

Zukas: Actually, I heard Linda Rosen of the exhibit on the disability movement in Berkeley, which she organized for the Berkeley Historical Society, talk about this at the opening, and Ed Roberts' attendants were doing that.

Bonney: Oh, so you were not ever involved in doing that?

Zukas: I may have been responsible for one.

Bonney: Where is that one?

Zukas: At Dwight and Dana.

Bonney: Do you know if Eric Dibner used to go out in the dark of night and do this?

Zukas: Linda Rosen said he was responsible for one or two.

Bonney: But you don't know from first-hand experience?

Zukas: No.

Bonney: I wanted to go back to something you said earlier--

Zukas: You know he's back here?

Bonney: Yes.

Earlier, when I asked you if you were a co-founder of CIL, you were quick to say no. But you were in that May meeting, and you were in the early years. Are you a co-founder?

Zukas: I don't think I ever said I wasn't. Are you thinking of my saying that I don't consider Ed as a co-founder?

Bonney: No, I thought when we started talking that you were saying that you didn't consider yourself one of the co-founders of CIL.

Zukas: I do.

Bonney: You do. Great. [chuckles] The other thing that you said is that one of the first services that CIL provided was financial benefit advocacy. Advocacy with which groups?

Zukas: I think around attendant care and income support. My memory of which services were provided at the beginning is very hazy. I have a better memory of our political activities.

Bonney: Why don't you tell me about those?

Zukas: The first major demonstration--well, maybe I shouldn't say "major"--was in front of the HEW building in San Francisco on the day before the '72 election to protest Nixon's veto of the Rehab Act of '72.

Bonney: CIL held a protest?

Zukas: Well, actually, we set up the Disabled and Blind Action Committee as our political arm.

Bonney: Of CIL.

Zukas: Yes.

Bonney: So who were members of the Disabled and Blind Action Committee? Yourself--

Zukas: Herb, Ed, and Phil Draper.

In-Home Supportive Services History

Bonney: So what else did this group do?

Zukas: Ah, yes--we get into HR1, which was Nixon's welfare reform. At that time, the income maintenance program for disabled people was known as Aid to the Totally Disabled [ATD], which was determined on a semi-individual basis. So when California established an attendant care program in the late fifties, they did it just by adding a supplement to the ATD check. And people were responsible for hiring their own attendants. So in '72 HR1 was enacted, under which ATD would be replaced by Supplemental Security Income [SSI] as of January 1, '74. SSI was to be a flat grant regardless of individual circumstances. Well, as it happens, that's not entirely true. To this day, I think blind people get more, and I believe that in Colorado at least, people can get a supplement to their SSI for attendant care. But that--

##

Bonney: We were talking about the SSI in Colorado, being able to get some extra money for attendant care.

Zukas: But that's way down the road.

Bonney: Okay. So what was the Disabled and Blind Action Committee's concerns with all of this?

Zukas: Twofold. Well, actually, threefold. One was to get SSI--wait --HR1 provided that there would be a flat federal payment, but

the state had the option of adding a State Supplemental Payment, or SSP.

So our concern was, one, getting a decent SSP; two, establish a mechanism for providing attendant care which allowed people to hire and fire and pay their own attendants; and three, to raise the maximum allowance for attendant care substantially. One of things I still remember was driving down I-5 in the yellow PDSP van at eighty-five miles an hour to a statewide conference--

Bonney: Where was the conference?

Zukas: In Long Beach, to plan a strategy around the implementation of HR1.

Bonney: What was the strategy that the group came up with?

Zukas: Actually, those three points were what came out of that meeting.

Bonney: Then how did the California group impact HR1? What did you do?

Zukas: HR1 was already law. The issue was how to implement it in California.

Bonney: Is this when you were in going to Sacramento and working with Phil Burton? Is this the issue?

Zukas: His little brother.

Bonney: John?

Zukas: Yes.

Bonney: Okay, so you worked with John Burton in Sacramento.

Zukas: George Moscone, who was in the senate, and whose AA [administrative aide] was George Miller.

Bonney: George Moscone's aide was George Miller?

Zukas: Yes.

Bonney: So what did you do with Moscone and John Burton in Sacramento?

Zukas: I got them to write bills to our liking.

Bonney: Did you get your three points in the state law?

Zukas: A group of us were in Sacramento virtually every week lobbying.

Bonney: How long did this take? How long was the process?

Zukas: The legislature had to adjourn on September 15. The Democrats were ready to give us what we wanted; the administration wasn't. By the way, in the last couple of weeks, I've been going through my archives looking for stuff for Linda Rosen, and one of the things I came across was a five-page single-spaced letter to a Republican swing vote on the Senate Finance Committee.

Bonney: What was his name?

Zukas: Donald Grunsky.

Bonney: And he was a state senator?

Zukas: Yes. By the way, I don't know if you have heard of a guy named Larry Agran who ran for president in 1992 in the Democratic primary. Well, anyway, in 1972 he was chief consultant for the Senate Health and Welfare Committee. He actually wrote the bill. The home health industry was arguing that they should be the ones providing attendant care, so we had to struggle against that. Anyway, toward the end of the session there were negotiations between the Democrats and the Reagan administrators.

Bonney: Reagan was governor during this time?

Zukas: Yes. They were not fruitful, and the legislature adjourned without passing a bill.

Bonney: So when you wrote to Grunsky as the swing vote, he didn't vote for it? Or what happened there?

Zukas: I think he did. But in any case, there was not a two-thirds majority. So then the administration announced they really didn't need legislation at all, that they could do it all by regulation.

Bonney: They shouldn't have said that, should they? [laughs]

Zukas: As I said in my speech at his memorial service a few weeks ago, Ralph Abascal said, "Oh, no, you can't." And he sued. Another thing I remember was going to the Court of Appeals in Sacramento in November, where he made mincemeat out of the administration.

Bonney: "He" meaning Ralph Abascal?

Zukas: Yes.

Bonney: Are we talking '72, or are we into '73?

Zukas: This is all '73.

Bonney: Okay.

Zukas: In November, less than two months before SSI was going to go into effect--

##

Zukas: --so the legislature was called into special session in the first week of December.

Bonney: When did this all get passed? When was it approved?

Zukas: The first week of December.

Bonney: Of '73. And this was the start of the IHSS [In-Home Supportive Services] program as we know it now?

Zukas: Yes. There were several compromises. One was that the counties were given the option of using independent providers, contract agencies, or their own employees to provide attendant services.

Second, I believe that we had asked that the maximum allowance for attendant care be raised from \$300 to \$450 and that we continue to get payment in advance. What the law actually did was to specify that for those who needed at least twenty hours a week of specified personal care services--it's a definition that just happens to fit the people that had been lobbying--that maximum would be \$450, and they had a right to advance payment. But for people who had fewer than twenty hours of personal assistance services, the maximum would be \$350. Oh, yes--we also demanded cost of living adjustments. While we got that in the law, that has been interpreted as applied only to the maximum, not to the amount that everyone got.

Bonney: So as a group, were you able to get all of these compromises into the law? This is what actually got approved?

Zukas: Yes. Five months after all this went into effect, I moved into my own apartment with Eric Dibner. That was no coincidence.

Bonney: You moved in after you were able to get the monthly attendant support?

Zukas: Yes.

Bonney: So that program helped you move out and live independently.

Zukas: Yes.

Bonney: Any other comments on this topic or things you want to say? Were there particular people, Hale, in the state legislature who were helpful or who were stumbling blocks? You mentioned that George Moscone helped and John Burton and a couple other people were swing voters and that sort of thing, but it sounds like the Reagan administration was not too supportive of this-- or is that a wrong interpretation?

Zukas: Right. [laughs] But the guy who carried the administration bill is now the head of the Department on Aging.

Bonney: And is that Agran, or is that someone else?

Zukas: No. Dixon Arnett.

Bonney: So he was the Reagan administrative person who--

Zukas: No. He was a member of the Assembly at that point. There were Democratic majorities in both houses. So the chairman of the Senate Health and Welfare Committee was Anthony Beilenson, who just retired from Congress. And Larry [Agran] worked for him. Did I say that Larry was probably responsible for writing--

Bonney: Yes, you did.

Zukas: One more thing: the guy who oriented us to the legislature was Bob Rosenberg.

Bonney: He oriented you to the legislature? How did he do that?

Zukas: He told us how it works.

Bonney: What was his title? What was his job?

Zukas: I forget. The last time I ran into him was several months ago, and he asked if I knew how Ralph Abascal was.

[Interview 4: April 16, 1997] ##

Bonney: Hale, we were talking last time we met about the IHSS program and how it came into law in 1972 and '73. That law put in place an attendant program that allows people with disabilities to live at home instead of in institutions, and in its current form people with disabilities hire, train, direct, and fire their own attendants. But there are attempts now to develop public authorities under county supervisors, which would take over the IHSS programs and possibly change how they work and how people get attendant care, et cetera. Could you tell me if you're involved with this activity at the moment and your thoughts on it?

Zukas: I'm on the advisory board of the Alameda County Public Authority. It so happens that in Alameda County the governing body of the public authority is made up of the members of the board of supervisors. Under the law, this is only one of three forms that a public authority can take. In San Francisco, the public authority is a completely separate entity which is made up of a majority of consumers.

Bonney: The Alameda County board is not made up of a majority of consumers? It's mostly the supervisors?

Zukas: It is the supervisors. But the advisory board is made up mostly of consumers.

Bonney: Okay. And the advisory board works with the board of supervisors as the authority.

Zukas: Yes.

Bonney: So what are the issues going on now around changing the IHSS program?

Zukas: Over the years, it has become apparent that while the IHSS program has the great strength of allowing consumer control, it also has a number of weaknesses. At least in most counties, it lacks an effective mechanism for bringing consumers and prospective personal assistants together, otherwise known as a registry. And there's no mechanism for providing training to attendants or to consumers when training is desirable. And there's no effective mechanism for providing attendants on an emergency or short-notice basis when one's regular attendant doesn't show up or is not available. Last but not least, wages are too low and there are no benefits for individual providers. Some counties have established what is known as "supported independent provider mode," which varies from county to county,

under which--by the way, that's not an exhaustive list of shortcomings in the IHSS program.

Bonney: These are the major issues?

Zukas: Yes. So some counties have established the supported independent provider mode, which furnishes one or more of the three services mentioned that are lacking in the IHSS program. It varies from county to county. The thing about public authorities is that they provide a mechanism for collective bargaining. It was the Service Employees International Union [SEIU] that came up with the concept of public authorities in the first place.

Bonney: What are your feelings, Hale, on these different issues? Let's talk first about whether there should be a registry. Are you in favor of that? If so, how will it help?

Zukas: Well, by providing a kind of clearing house, it makes it easier for disabled people to find attendants and vice versa.

Bonney: Now, how would the registry be put together? Would somebody in the public authority oversee its production and do it? How would it work?

Zukas: It could do it in-house. It can also do it as it's done in Alameda County, where the public authority contracts with six nonprofit agencies.

Bonney: So the registry would be a collection of names of people who want to do attendant work. Would they be screened in any way before they could go on the registry?

Zukas: Yes. There is an intake process where people fill out an application indicating what times they are available, whether they drive, what kind of tasks they can or are willing to do, what languages they speak and so on.

Bonney: Would someone screen these applicants' backgrounds to be sure they weren't murderers or thieves or whatever? I know that's an issue that comes up.

Zukas: Yes, that is an issue. Someone in the Assembly introduced a bill last year to require that all prospective providers of personal assistance get a fingerprint check. Disability groups and SEIU opposed that bill, and it was amended to become virtually meaningless.

##

- Zukas: But this year Assemblyman [Tom] Woods [Jr.] reintroduced the bill requiring prospective attendants to have fingerprint checks. And I had planned to go up to Sacramento yesterday for the first committee hearing, but the bill was pulled from the agenda.
- Bonney: What is the disability community's opposition to this bill to having fingerprint checks done?
- Zukas: Three things. One is that it takes a long time to get the fingerprint checks done. It costs thirty to fifty dollars, and as far as we know, there's no evidence that it reduces the amount of abuse.
- Bonney: And one last question on this issue: who would actually do the fingerprint check? Would you, as the potential employer, have to initiate it? Or would some agency do it?
- Zukas: Are you asking who would initiate or who would actually do the check?
- Bonney: I guess I'm asking what the process would be if you were going to, under this system, hire a person, and you needed a fingerprint check done on that person so you could hire them. What would you as the consumer have to do?
- Zukas: I think that bill only requires--do you want me to look it up?
- Bonney: No, that's okay.
- Zukas: I think the bill only requires that prospective attendants have fingerprint checks before they go to work.
- Bonney: And right now this bill is not connected with the registry that people are talking about under the public authority. They're separate?
- Zukas: Right.
- Bonney: Let's go on to the other thing under the public authority, and that is the training issue. If a public authority began training attendants, I'm assuming that they would give them just basic knowledge and understanding of how to do transfers, how to bathe, that sort of thing. Do you think that that will move the system towards a medical model if some other entity does training?
- Zukas: All training would be optional. Some disabled people might want attendants with no formal training. Some people might want people who have been oriented to what attendant work is

and some of the basics, as you said. And other people might not feel they want or are able to train their attendants, and might want someone with more extensive training. There would also be optional training for disabled people in how to manage their attendants.

Bonney: Would the people doing the training of the attendants and working with people with disabilities--would they be consumers doing the training?

Zukas: Largely, but not necessarily entirely by disabled people. For example, you probably want a non-disabled person teaching people good lifting techniques.

Bonney: One of the things that I have read, Hale, about this issue is that there's been talk that prospective attendants would unionize. What are your thoughts on that?

Zukas: Muddled, because I have a fundamental conflict of interest.

Bonney: Can you explain that?

Zukas: Well, on the one hand, I'm in favor of workers having an effective mechanism for pursuing their interests. On the other hand, I want control over--I am jealous of my prerogative as an employer.

Bonney: Part of the unionizing issue, of course, is that wages are too low. You said when we met last week, if I can remember correctly, that the people with the most need under the IHSS program get \$450 max. Or was it \$400?

Zukas: No, that was in '74.

Bonney: Oh, has it been increased over the years? You also said that there was sort of an inflation or cost of living element to it that has been largely ignored. What now could people get on a monthly basis?

Zukas: The law was written to provide that there would be a COLA [cost of living adjustment] in the maximum allowance every year. Our intention was that attendant wages would have a COLA, but the state's position was that the law requires only a COLA in the maximum amount. Until the early eighties, counties were allowed to set their own rates. Then in the early eighties the state set it at the minimum wage, while grandfathering in those counties which were above the minimum wage.

Bonney: So all a regular attendant gets at this point--in most cases-- is minimum wage from the state, and the consumer can augment if they want to or can. Is that the situation now?

Zukas: By whatever means. [laughter]

In the late eighties, I believe, when the minimum wage went from \$3.35 to--

##

Bonney: So you were saying, Hale, in the late 1980s--

Zukas: The minimum wage went from \$3.35 to \$4.25, and the maximum amount was changed from a dollar amount to the number of hours allotted.~ If that hadn't been done, people who were at or near the maximum would have had a sharp cut in hours.

Bonney: Let's assume that somehow attendant wages under this new system are increased. Do you think that the state will increase the total amount of dollars that they put towards this program so that hours don't get cut? Or will hourly rates go up and hours of service go down? What are your thoughts on that?

Zukas: Everybody involved agrees that increasing wages and benefits should not be accomplished by reducing hours.

Bonney: What do you think the state would do if attendants collectively bargain and they win, and rates go up? What do you think the state would do?

Zukas: Right now counties are free to raise wages, and San Francisco has in fact done so.

Bonney: So it would come out of the county budgets--any increase.

Zukas: Well, yes--right. The state just won't pay their share; the feds will.

Bonney: The feds will pay their fair share to the states, you mean?

Zukas: Well, okay. Did I talk last week about how in 1992 the state put most of the IHSS program under Medicaid?

Bonney: No, you didn't talk about that.

Zukas: Okay. We'll detour. In the seventies there was one legislative aide who kept saying we ought to pull Medicaid money into the IHSS program.

Bonney: This is a state legislative aide?

Zukas: Yes. We resisted because we thought that service under Medicaid had to be provided by agencies, with a lot of medical involvement. In the late eighties, WID did a study of Medicaid programs and found that while some programs under the so-called "Personal Care Option" were highly medicalized, others were not, and that HCFA [Health Care Financing Administration] regulations on the PC Option were about three lines long. In 1991, you remember California had a severe budget crisis. Well, the 1991 budget bill required that the state Health and Welfare Agency set up an IHSS and Long-term Care task force to develop ideas for better and more efficient services. And WID was appointed to this task force, and largely because of our influence, the task force recommended that the Medicaid state plan be amended to include personal care. And one of the people who worked on the WID study worked with the state on writing the amendment.

Bonney: Who was that person?

Zukas: Jae Kennedy. He wrote the amendment in such a way that the Medicaid part of the program would be as similar to the existing program as possible. I believe that took a year and a half. By the middle of '93, California was getting something like a third of a billion dollars a year--

##

Zukas: --billion dollars in Medicaid funds. Something like 65 to 70 percent of IHSS recipients are eligible for what is called the "Personal Care Services Program [PCSP]," for which the feds pay half the cost. When San Francisco raised their wages, the feds paid half the cost for the people who are on PCSP.

Bonney: Hale, where is the push coming from now to look at IHSS and how everything is done and perhaps change it? What's behind it? Or who's behind it?

Zukas: What do you mean?

Bonney: I mean, is it the counties that are worried about the expenditure of funds in their programs that they're running, and are they the ones that are looking to change how it's now done? Or is it consumers pushing for it to change, or is it the state saying it's too expensive? Where's the push coming from?

- Zukas: On one side, there are disability advocacy groups, SEIU, and public authorities pushing for improvements in the independent provider mode. Did I say there were three modes for providing personal assistance? For providing IHSS?
- Bonney: I don't believe so, no. Maybe we can stay on this subject for a second. So the SEIU and consumer advocacy groups and the public authority are pushing to have sort of independent contractor modes. Is that right?
- Zukas: They're pushing for improvements in the individual provider mode. In the IP mode. IP is one of three modes. Contract agencies are another, and county employees are another mode. But that's negligible--the county employees is negligible. All counties have some IP providers.
- Bonney: Is IP the mode that you're operating under now? Is that what it's called?
- Zukas: Yes. And something like eleven counties also have contract agency providers. Years ago, all those contracts were with one agency: National Home Care, which is now Addus. I suspect they changed their name because they had developed such a bad image. Anyway, along with their company union, the United Domestic Workers, Addus has been pushing various schemes to get a bigger share of the market.
- Bonney: In all of this, Hale, what do you hope happens?
- Zukas: You mean what I would like to see?
- Bonney: Yes. How would you like this to resolve itself?
- Zukas: An IP mode with all the ancillary services I talked about at the beginning, and where no one has trouble getting attendants.
- Bonney: Do you think if you got the IP mode and the ancillary services, is there a chance that consumers would still have reduced control over their attendants? Or would it become more of a medical model?
- Zukas: The idea is that there would be a menu of ancillary services from which to choose, and all of them would be optional.
- Bonney: So in effect if you wanted to keep the attendant care program you have right now, the way you have it, you would be able to do that under these changes.

Zukas: Yes. I should say I have been looking for attendants for more than a year. I have been keeping my personal fatigue with that process out of the discussion.

Bonney: With the process of finding attendants?

Zukas: Yes.

Bonney: Let me ask you one last thing quickly, Hale. Some of this has been categorized in disability magazines as an attendant care crisis. Are we in a crisis, in your opinion?

Zukas: Maybe. Tell me more.

Bonney: I read an article in, I think it's New Mobility, and it came out probably in fall or winter. It was mostly talking about this problem down in L.A. and what they're doing. They're sort of categorizing it as a statewide crisis of consumers losing control of attendant care, and the price will go up if it gets unionized, and the hours will get cut, and things will get really bad. Is that your opinion of where we're headed?

Zukas: In that context, yes, I think there is a crisis. There are two sides that are polarized in the fight in L.A., and I think one side is saying "it ain't broke, so don't fix it."

Bonney: Are the consumers saying that? Is that the side saying it's not broke?

Zukas: There are consumers on both sides.

Bonney: So it's sort of a mixed bag of differing opinions.

Community Affairs Coordinator for CIL: Picket Lines and Curb Cuts

[Interview 5: April 23, 1997] ##

Bonney: I'd like to go back this morning to the early seventies and the startup of CIL. Earlier, we talked a little bit about how you and others started CIL around 1971, and you had mentioned that originally it was a desk at PDSP. Could you tell me a little more about how CIL was run out of PDSP and what kinds of things were being done at that point?

Zukas: First, we were fleshing out our conceptions of what CIL should be. We incorporated, and we were looking for money. I think I

talked earlier about one of the two times in my life when I had stayed up until dawn working on a proposal for Tom Joe.

Bonney: Tell me what the original conceptualizations were for CIL.

Zukas: Basically, what PDSP was doing for the students--to have that available for the community. That is to say, to provide some of the services that significantly disabled people will need to live in the community.

Bonney: Can you give me examples of those services?

Zukas: Three come to mind: financial benefits advice and advocacy, attendant referral, and wheelchair repair.

Bonney: Did CIL try to establish one or two or three of those right away? What were the first services they tried to focus on?

Zukas: As I recall, we didn't actually start providing direct services until '73 or '74.

Bonney: And by that time you had moved out of PDSP, is that right?

Zukas: Oh, yes. Our first funding was a \$50,000 planning grant from the Rehabilitation Services Administration.

Bonney: Is that Mr. Tom Joe?

Zukas: No. I think Herb Leibowitz was involved. The regional administrator was Dale Williamson.

Bonney: Now, at some point, did you use this \$50,000 fund to get the first CIL office and sort of organize yourselves into an entity?

Zukas: Yes.

Bonney: Okay. And then at some point, CIL received a grant from the city of Berkeley. Can you tell me about that?

Zukas: You mean for direct services?

Bonney: It was a community development block grant for about \$19,000. I thought it might have been used for housing, but I'm not sure about that.

Zukas: When was this?

- Bonney: I don't know the date, but it was in the early to mid-seventies. You don't know anything about that?
- Zukas: No. We did get some money for our housing component, but I think that was in the mid- to late seventies. I went through some of my archives looking for stuff which might be of use to the Berkeley Historical Society exhibit and I came across the proposal to Tom Joe, and part of a proposal to the city of Berkeley, and I think that was for funding our services to Berkeley residents.
- Bonney: At some point, the CIL established a transportation and access community affairs position. You, I believe, were the director of that, and Eric Dibner worked with you as your assistant?
- Zukas: Well, I don't think Eric was ever officially my assistant. In 1972, I was involved with the city on curb ramps, and Larry Biscamp and the other higher-ups thought I had a knack for dealing with government agencies. So when we got the RSA grant, they put me on staff as the coordinator of community affairs.
- Bonney: What did you do as coordinator of community affairs?
- Zukas: At first, work on improving architectural accessibility.
- Bonney: In terms of transportation or buildings or what?
- Zukas: Buildings.
- Bonney: City buildings?
- Zukas: Yes.
- Bonney: What buildings did you work on?
- Zukas: The elevator at City Hall. I remember a county building in Hayward.
- Bonney: So CIL was not focusing just on Berkeley then.
- Zukas: No.
- Bonney: What other issues did you work on as community affairs director?
- Zukas: The first time I remember that we got politically active was when Nixon vetoed the Rehab Act of '72 and we organized a

demonstration at the HEW building the day before the '72 election.

Bonney: Was this a big demonstration?

Zukas: As I recall, yes.

Bonney: About how many people were there?

Zukas: My guess is about thirty.

Bonney: What activities did the group do when they were at the HEW building?

Zukas: There were speakers--

##

Zukas: --set up a picket line.

Bonney: Who were the people that spoke?

Zukas: I don't remember. It seems to me that Judy Heumann was one.

Bonney: What did you do specifically to help organize this demonstration?

Zukas: I think strategizing. I'm feeling more and more like a klutz.

Bonney: Why? [laughs]

Zukas: Because I don't remember most of the things you are asking.

Bonney: That's okay. I assume this was a peaceful demonstration?

Zukas: Yes. We created the Disabled and Blind Action Committee as our political arm.

Bonney: This was one of their activities then? Because we talked about that a little bit earlier.

Zukas: Yes.

Bonney: Tell me what your impressions were of how the city of San Francisco responded to a demonstration back in '72 of people with disabilities. It was not as common as it might be now.
How did the city respond to that?

Zukas: I don't remember.

Bonney: Was there a lot of police presence?

Zukas: I don't remember. [laughter] I don't think so.

Bonney: All right. Let's go back and talk about curb ramps for a couple of minutes. You started saying today that you were working on curb ramps with the city of Berkeley. Can you tell me what that project was, what it involved, and how you identified curbs to be ramped, et cetera, and how they actually came to be ramped?

Zukas: This was one of the questions that Linda Rosen asked me, so I did some research. First, the city rebuilt Telegraph [Avenue] in 1969 and the Rolling Quads found out, and they went to the city and asked them to make--by the way, this was between Bancroft and Dwight [Ways]. The Rolling Quads asked them to make the curbs accessible.

Bonney: What was the city's response?

Zukas: I can't say exactly, but it was done.

Bonney: So the first curb cuts in the city of Berkeley were on Telegraph Avenue.

Zukas: Anyway, Eric tried to find out when it was. I asked Eric when it was done, and someone found as-built drawings dated January 1970.

Bonney: The Telegraph Avenue work was done in 1970.

Zukas: Probably 1969.

Bonney: This coming Friday, Hale, there's a celebration to commemorate the first curb cut, and this celebration is saying that the curb cut on Center Street--and I forgot the other corner--

Zukas: Shattuck.

Bonney: And Shattuck. That isn't the first curb cut, is it?

Zukas: It might have been that the curb ramps on that section of Telegraph have all been replaced, so it might be. I came across a list of locations which I think was the next series that we asked the city to do. The ramp at Shattuck and Center looks more primitive than those, so it might be the oldest existing curb ramp. In any case, I consider that the twenty-fifth anniversary celebration is a couple of years late.

Bonney: And the twenty-fifth anniversary you're speaking of is of what?

Zukas: Allegedly, the first curb cut.

Bonney: I've been told that when you started working with the city originally on curb cuts, you would identify the suggested places and you would tell the city traffic engineer, I think-- Chuck [Charles] DeLeuw--where you wanted the places, and the city would dump asphalt at night if they had asphalt left over from other projects.

Zukas: Chuck DeLeuw did come to a meeting at the CIL apartment, but that was long before. Did you call him city engineer?

Bonney: City traffic engineer? I'm not sure of his title.

Zukas: That was long before he became traffic engineer. That was when he was working for DeLeuw-Cather, which is a big civil engineering firm. They were developing the Berkeley Neighborhood Traffic Plan. At the outset, the Berkeley city engineer was named Bill Dabel [spells]. In '71, we went before the city council and asked for fifteen more curb ramps. In '72, we asked them to pass a resolution to make all corners accessible and to allocate \$30,000 a year for curb ramps. They passed the resolution, but said that the allocation should be part of the budget process. I developed a curb ramp design which was used by the city--

##

Zukas: I developed a curb ramp design that was used by the city for ten years or so, and until they adopted the design in Title XXIV. And for a few years they developed a list of curb ramps which they submitted to me for approval.

Bonney: I just want to clarify one thing. Did they put the \$30,000 a year in the regular budget process for curb ramps? Did they actually do that?

Zukas: I don't know that it was \$30,000, but every year they awarded a contract.

Bonney: What was your curb ramp design? What did it look like?

Zukas: It was four feet deep by eight feet wide, which in a standard six-inch curb is obviously much steeper than the one in twelve, which is the universal accessibility standard.

- Bonney: Did it cut the sidewalk out or cut back into the sidewalk? Or did it lay cement or something around the curb and fan out?
- Zukas: It was cut into the sidewalk. As part of our cross-disability consciousness with curb ramps, curb ramps were put outside the crosswalk. So there would continue to be a curb in the regular path of travel to alert blind people that they were about to step into the street.
- Bonney: Do you like that system better than the one we have now where curb cuts are ridged to warn people when they're going into the street?
- Zukas: Yes, because most blind people regard the grooves as virtually useless.
- Bonney: What do you think moving the curbs into the crosswalk has done for people for use wheelchairs?
- Zukas: Two things. It means we don't have to go out of our way as much, but there is more of a jolt because of the lip. And more importantly because of the angle between the ramp and the gutter. One of the nicer things about my design is it specifies that the transition between gutter and ramp be a four-foot radius vertical curve.
- Bonney: When Title XXIV was being developed, did you try to get your curb ramp design implemented at all?
- Zukas: I think so.
- Bonney: And it wasn't accepted for some reason?
- Zukas: Yes.
- Bonney: What were the objections, do you remember? Were you part of discussions about this?
- Zukas: To some extent.
- Bonney: Did the people explain why your design was not used?
- Zukas: Not that I remember. But I think the fact that it was out of the normal path of travel must have a lot to do with it.
- Bonney: Who were you talking with around Title XXIV? Who were the players?

Zukas: State Architect Barry Wasserman, at the time that they were being developed.

Bonney: Hale, are there examples of your curb cuts still in Berkeley?

Zukas: Yes.

Bonney: Where are some of them? Can you give me locations?

Zukas: On Telegraph south of Dwight.

Bonney: On both sides of Telegraph?

Zukas: Yes.

Bonney: Okay. ~

Zukas: It's very spotty because some have been redone.

Bonney: Is there truth to the story that you would identify places for curb cuts and then the city would put asphalt at the end of the workday if they had asphalt left over from other jobs?

Zukas: Perhaps, when the curb was less than two inches high. An example is at Shattuck and Russell. There are some locations where they have put in curb ramps where they're not needed. For example, at the corner right out here, which is the corner of Stewart and Milvia--our corner--where the concrete has been cut across. I saw that after they did it, and I called and told them there was no reason to put one. And for a number of years the city was not putting in any asphalt ramps. I hear they are reconsidering that. Eric hired a guy to do what should be the ultimate survey of all the corners in the city.

Bonney: That's being done now?

Zukas: Yes.

Bonney: Are you working on that?

Zukas: No. I thought of applying.

Bonney: Why didn't you? You'd be great.

Zukas: Well, I decided that the notetaking was too complicated.

III 504 SIT-IN, ARCHITECTURAL AND TRANSPORTATION BARRIERS COMPLIANCE BOARD, AND SEVERAL STUDIES

Participation in the 504 Protests, San Francisco and Washington

[Interview 6: May 7, 1997] ##

- Bonney: Hale, I'd like to talk today about the 504 rally and sit-in and the issues around that. My understanding is that you participated in the sit-in in the building until you went to Washington. Is that right?
- Zukas: Yes.
- Bonney: Can you tell me how you got involved with the sit-in and what you were doing what it started?
- Zukas: Actually, I only remember I was in a position when I hardly could not have participated. That is, I was at CIL as the coordinator of community affairs, so I was near the center of things.
- Bonney: What were you doing as the coordinator of community affairs?
- Zukas: The standard phrase I used at the time was "working to improve the physical and social environment for disabled people." That is, working to remove physical barriers and working in the political arena for legislation and regulations that would benefit disabled people.
- Bonney: What activities did you participate in as part of pre-planning for the sit-in?
- Zukas: I remember going to a few planning meetings, mainly held across Telegraph from CIL at DLRC [Disability Law Research Center].

Bonney: Who led these meetings?

Zukas: Jim Pechen.

Bonney: So Jim Pechen was running some of the meetings. What was his function? Was he at CIL at that point?

Zukas: I think he was head of DLRC.

Bonney: Were Kitty [Cone] and Judy [Heumann] and Mary Lou [Breslin] in these meetings?

Zukas: Yes.

Bonney: What kinds of things were they involved with? Tell me what Mary Lou was doing.

Zukas: The reason I remember that she was the employment counselor on campus for disabled students--the reason I remember that is the night before the rally she was in her office helping me do my application to be executive director of the ATBCB [Architectural and Transportation Barriers Compliance Board].

Bonney: So that was the position in Washington, correct?

Zukas: Yes. I would have had to have gone to Washington.

Bonney: Now, at this point Mary Lou wasn't still working at UC Berkeley, was she?

Zukas: Why do you say that? I just said I was in her office in Building T9 [where the Career Planning and Placement Office for Disabled Students was located].

Bonney: So in April of '77 then, Mary Lou was still working at UC and not at DLRC. Is that correct?

Zukas: Yes.

Bonney: Okay. I'm just trying to get the time sequence here.

Now, at these meetings then, what did Mary Lou do in these planning meetings?

Zukas: I only remember that they were planning meetings. I assume she was one of the leaders.

Bonney: Do you remember any specifics of what Kitty was doing to pre-plan the sit-in?

Zukas: She may have been the one in charge of media relations. Why don't you wait until one-thirty and ask Mary Lou?

Bonney: What's happening at one-thirty?

Zukas: She's going to be here.

Bonney: Oh. [laughs] Somebody else is asking Mary Lou these questions --not me. [laughs]

When you were all planning the rally, and the morning that you went to the rally, had a group of you or all of you decided to sit in before you went?

Zukas: Well, let me put it this way: they had decided to be prepared to sit in.

Bonney: When you say "they," was this a small, core group of people or was this generally known that--

Zukas: I don't remember. My vague recollection is that it was more than the core.

Bonney: Did this group of people who were preparing to sit in if necessary--did you bring stuff with you to stay there? Did you know it would be twenty-five days long, and did you bring stuff to wear and toothbrushes and stuff like that? What did you do to prepare to sit in?

Zukas: I remember bringing my raggedy sleeping bag and a banana.

Bonney: So you thought maybe an overnigher! Do you like bananas? [laughter]

Zukas: Yes.

Bonney: Hale, tell me what your impressions are of walking up into the United Nations Plaza [outside the Federal Building in San Francisco] the day of the first rally. What was going on, and how did you feel about what was going on?

Zukas: I don't remember.

Bonney: Were there a lot of people there?

Zukas: Yes.

Bonney: How many would you estimate were outside the [Federal] building at the height of the rally?

Zukas: Oh, 100 to 200.

Bonney: And what were they doing?

Zukas: There were some speakers, and we walked in a circle. At some point we went in.

Bonney: You went into [Joseph] Maldonado's [regional director of Department of Health, Education and Welfare] office. Did you all have an appointment with him? Is that how you got in? What happened there?

Zukas: I don't remember.

Bonney: Do you have a recollection of just sort of all of you crashing into his office unannounced, or was it orderly?

Zukas: My guess is that we were pretty insistent on seeing him and that they acceded.

Bonney: Were you one of the people in Maldonado's office?

Zukas: I think so.

Bonney: Was Judy the leader or the spokesperson?

Zukas: Yes.

Bonney: What did she say to him?

##

Zukas: I know what she would have said. I don't know whether I can say it's actual memory or reconstruction, but she probably told him to urge [Secretary of Health, Education and Welfare Joseph] Califano to sign the regulation.

Bonney: How did he react in this meeting?

Zukas: My guess is that he was pretty amenable.

Bonney: Did he or any of the other HEW officials or staff that you saw during the sit-in seem afraid of you guys?

Zukas: I can't say, although it's obvious that they were. If they had wanted to get us out they could have done so.

Bonney: But you think they didn't put you out because they were afraid.

Zukas: Yes.

Bonney: That first day, when you were rallying outside and then went into Maldonado's office, what was the media doing? [tape interruption]

Zukas: These are the famous Ken Stein tapes.

Bonney: And these are tapes of tape recordings of media coverage during the event, is that right?

Zukas: TV.

Bonney: Oh, just TV coverage. All right. And these are four audio tapes?

Zukas: Yes.

Bonney: Does the 504 Committee know about these tapes?

Zukas: Well, I would assume.

Bonney: I wonder. I don't know if they do or not, or if they might want to use them somehow.

Zukas: Isn't Ken Stein co-chair?

Bonney: He's chair, yes. [tape interruption]

Hale, did the media interview a lot of people that day? What kind of activities did you see the media doing?

Zukas: Yes, I think so.

Bonney: Tell me what happened when the group was in Maldonado's office and they decided that they were going to stay and sit in.

Zukas: I don't remember. I have less trepidation about saying "I don't remember" in this conflict because there are lots of other sources you can draw on.

Bonney: It's okay if you don't remember. That's fine.

There was an account in a couple of the newspapers that HEW officials were told that before you all left Maldonado's office you should be given cookies and punch before you were sent home. Did you get cookies and punch?

Zukas: I don't remember. [laughter]

- Sprecher: If you had gotten cookies and punch you would have remembered, Hale. [laughs]
- Bonney: Hale, while you were in the sit-in, what were the physical conditions like? How did you sleep? How did you eat? How did you get a bath? How did you go to the bathroom? What was life like?
- Zukas: I can't believe I can't even remember how I went to the toilet.
- Bonney: Did you have an attendant go in with you?
- Zukas: My live-in attendant at that time was named Tom Wanning.
- Bonney: Was he in the building with you?
- Zukas: Yes. He was enthusiastic enough about it that he may have been there more for his own reasons than to help me.
- Bonney: But did he serve as your attendant?
- Zukas: Yes.
- Bonney: How did you all eat? After you finished your banana that you took with you, how did you all eat from then on?
- Zukas: We had a lot of donuts in the morning and a lot of McDonald's in the afternoons. But as I said, in my remembrance our secret weapon was the meals provided by the Black Panthers.
- Bonney: What kind of meals did they get for you?
- Zukas: Well, they were running a pretty large food program for school children, at least in Oakland, and they had their own kitchen. Two people in the sit-in were Brad Lomax, who was in a wheelchair--I'm not sure what his disability was; it may have been MS [multiple sclerosis]--and his friend Chuck Jackson. The two of them were members of the Black Panthers. They arranged for us to be provided fresh-cooked meals. I can't believe they were still hot by the time we got them--at least they were fresh.
- Bonney: What did you do all day long at the sit-in?
- Zukas: That's a good question, and one that I don't have an answer to, except to say there were a lot of meetings.
- Bonney: Tell me about the meetings. What were they about?

Zukas: What we should do next. Other than that, I can't say.

Bonney: Okay. In those meetings, how were decisions made? Did you all have to agree on it? Did a certain percentage of you have to agree on something to take the next step?

Zukas: I think it was by consensus.

Bonney: So not everyone had to like it, but you all agreed at some point on a next step. Is that right?

Zukas: Yes.

Bonney: Tell me how you were selected to go as part of the Washington contingent.

Zukas: I don't know.

Bonney: How were other people selected to go?

Zukas: I think mainly on the basis of political savvy and/or appearance.

Bonney: Physical appearance, you mean?

Zukas: Yes.

Bonney: Tell me more about that. What do you mean by that?

Zukas: I think they wanted people who were obviously disabled like me, and I think that consideration was a factor in my being picked.

##

Zukas: --on the basis of my appearance and because of my aptitude for working with bureaucracy.

Bonney: Did you want to go to Washington or did you want to stay with the sit-in?

Zukas: I assume I wanted to go. It occurred to me at some point that the other time I had been to Washington was when I was seventeen, and now I went again when I was almost thirty-four.

Bonney: Did you all go on the airplane together to Washington?

Zukas: * Yes.

Bonney: Tell me about that. I understand there were media watching everybody getting on.

Zukas: Yes. There was a crew from Channel 7 who went with us.

Bonney: Was that Evan White?

Zukas: Yes.

Bonney: So he went on the plane with you guys?

Zukas: Yes.

Bonney: It was unusual at that time for airlines to allow more than two or three people at one time with a disability on an airplane. How did you all get on the same plane?

Zukas: You mean why did United [Airlines] let all of us on?

Bonney: Yes.

Zukas: Well, for one thing, the plane was a DC-10, meaning it had a lot of room. One of the vice presidents of United was in a wheelchair, which helped.

Bonney: Who helped load everybody onto the plane? Was it airline staff that did most of it?

Zukas: I don't remember. But I haven't finished my answer. A machinist union [International Association of Machinists and Aerospace Workers, AFL-CIO-CLC] at the United maintenance base had become very interested in this, and particularly one named Willy was--I don't remember the last name; two names that come to mind are Banks and McGee. Willy Banks or Willy McGee.

Bonney: So did the machinists help get people on the plane?

Zukas: I don't remember.

Bonney: I know that there were some machinists that were with you in Washington. Did they come from San Francisco and go to Washington?

Zukas: Yes.

Bonney: And what did they do when you were in Washington?

Zukas: For one thing, they rented a big truck with one of those big lifts in back.

Bonney: And what did they do with the truck?

Zukas: That was what they used to transport us.

Bonney: What kind of a truck was it? Open-air, closed--

Zukas: Closed.

Bonney: Was it like a moving truck? A U-Haul kind of truck?

Zukas: Yes.

Bonney: Okay. And you all got in this truck and drove around Washington?

Zukas: Yes.

Bonney: Could you see out?

Zukas: No.

Bonney: Was it dark inside?

Zukas: Yes.

Bonney: I'm assuming they closed the doors.

Zukas: Yes.

Bonney: What was that like? What did that feel like?

Zukas: I wasn't wild about it.

Bonney: Were you tightly packed in so that you didn't roll around when you went around corners or stuff, or did you all sort of jostle around in there?

Zukas: I think we were fairly tight.

Bonney: Did you hang on to each other?

Zukas: Yes.

Bonney: And while you were being transported through the streets of Washington in this dark truck, what did you all do?

Zukas: I don't remember.

Bonney: Did you talk to each other? Did you sing songs? Did you scream going around corners? [laughs]

Zukas: Sometimes, yes.

Bonney: And you were transported by truck for how many days?

Zukas: About ten.

Bonney: Is that about the number of days you were all in Washington?

Zukas: Yes.

Bonney: What did you do when you first got to Washington?

Zukas: We went to a Lutheran church on Thomas Circle.

Bonney: Was this church home in Washington?

Zukas: Yes.

Bonney: What did the church members do for you other than give you a place to stay? How did you eat while you were in Washington? Did this group feed you? What accommodations did you have?

Zukas: That I don't remember.

Bonney: But you all slept there for the duration of the time that you were in Washington.

Zukas: I didn't stay all the time. I remember I learned that Califano had signed the regulations. Well, the way I heard was that Debbie Kaplan called just as Ralf [Hotchkiss] was trying to wrestle me into the wheelchair.

Bonney: Can we go back and clarify here? You said that you didn't always stay at the church. Then you said that you found out the regs were signed when Debbie called Ralf, who was wrestling you into your wheelchair. I lost the connection there.

Zukas: From the bed in their living room.

Bonney: Okay, so you went to stay with Ralf instead of staying in the church all the time.

Zukas: Yes.

Bonney: I think Brad and Chuck went back before some of the rest.

[Interview 7: May 22, 1997] ##

Bonney: Hale, let's continue talking about the 504 sit-in. When we left off last time, you were in Washington, and you were staying at Ralf's house when you found out the regs had been signed, and that's where we stopped. I want to go back just a little bit. When you got to Washington and you started meeting with the administration, what kinds of things were they putting up as roadblocks or what were they saying?

Zukas: I don't remember. Great start. [laughter]

Bonney: That's okay. Were you in the meeting with [Senator] Alan Cranston?

Zukas: Yes. ~

Bonney: Do you remember what happened there?

Zukas: You mean the one on the day after we arrived?

Bonney: I don't know if there was more than one meeting, but I've heard about one meeting where Senator Cranston sort of put forth the eighteen issues or roadblocks in the 504 that people were against or wanted to change. I think you met with Cranston, and maybe Ann Rosewater was in that meeting, and you discussed the issues.

Zukas: The one I remember is the one I kept falling asleep in because I had never gotten out of my chair the night before.

Bonney: Tell me about that meeting with Cranston. What happened there?

Zukas: All I remember is that Frank Bowe [Director of American Coalition of Citizens with Disabilities] made an eloquent speech.

Bonney: What did he say? What was the gist of his speech?

Zukas: That the regulations were our due.

Bonney: Do you remember if that was the speech where he said that people with disabilities were less than second-class citizens, they were third-class citizens?

Zukas: . Yes. I think so.

Bonney: Did anyone else talk in that meeting that you remember?

Zukas: I think other members of the delegation.

Bonney: Did you speak?

Zukas: No. I'm sure not.

Bonney: What was Cranston doing in the meeting? What were his concerns? What was his attitude or his demeanor?

Zukas: I'm sure he was supportive.

Bonney: Do you remember if he seemed to agree with the issues that had been raised, that they were the right issues, and that the regs should be changed? Do you think he felt that way when you went into the meeting?

Zukas: I don't remember.

Bonney: Tell me why you hadn't gone to bed the night before.

Zukas: I think we arrived at the church around midnight, then we had a meeting which didn't get over until around two o'clock, and we were supposed to be up early the next morning. I think we decided it just wouldn't be worth it.

Bonney: Was this before or after the candlelight vigil in front of Califano's home?

Zukas: Before, I'm pretty sure. We went directly from Dulles [Airport] to the church.

Bonney: Were you at the Califano vigil?

Zukas: There were several sessions.

Bonney: Were you at the all-night watch in front of his house?

Zukas: For some of it, I think. I don't remember an all-night vigil.

Bonney: Do you remember being in front of his home?

Zukas: Yes.

Bonney: How did the neighbors and the police react?

Zukas: I don't remember neighbors. I believe the police were pretty loose.

Bonney: So they didn't move in to arrest you or break you up or anything like that?

Zukas: Yes.

Bonney: When it was over, did you all just decide to leave at some point? How did the leaving of the scene occur?

Zukas: I believe it was time to go on to the next activity.

Bonney: I know you met with Cranston when you were all there. Did you meet with other legislators?

Zukas: I don't remember. Probably. I just don't remember.

Bonney: I know that when you found out that the regs had been signed you were at Ralf Hotchkiss' house. How did the general group of people find out that the regs had been signed, and what was the atmosphere when they found that out? What did everybody do?

Zukas: Not being there, I can't say, but I assume there was jubilation.

Bonney: How did you react? What did you and Ralf do?

Zukas: We whooped. [laughter]

Bonney: And how did Debbie find out? She called Ralf. Where was Debbie when she called?

Zukas: I don't know. She may have been in her office.

Bonney: How did the contingent get the word that the regs had been signed? Who called, or what happened that they found out?

Zukas: I don't know since I wasn't there.

Bonney: What was the plane trip like to go back to the HEW offices in San Francisco?

Zukas: That I don't remember. I didn't go back until people had left the building.

Bonney: Oh, you stayed in Washington?

Zukas: Yes.

Moving Into Own Apartment, 1974

Bonney: Those are the questions that I had about 504. Let's go back now to your days at CIL. We kind of got onto that and then we stopped and got off track a little bit. There was a committee called the Transportation and Access Community Affairs Committee or something like that that you directed, and I think Eric Dibner was your assistant. What was that office and what did you do? What issues did you take up?

Zukas: We worked on legislation and accessibility. I don't think Eric was actually my assistant at CIL.

Bonney: What issues did you work on? First of all, were they local transportation access issues or state issues?

Zukas: Mainly architectural access. Statewide. We worked on SSI and what was then called the Homemaker Chore Program, which is now IHSS.

Let me say a few things about Eric. He was the one who enabled me to move out on my own by agreeing to live with me.

Bonney: Tell me about that. When was this?

Zukas: That was in 1974.

##

Zukas: Well, in January, as I said, the maximum allowance for attendant care was raised from \$300 to \$450 a month. That made moving financially feasible, and Eric was living out of an old flatbed truck which he had built a house on, and it was parked near Ed Roberts' house where he spent a lot of time.

Bonney: Was Ed Roberts living on Eton Street then?

Zukas: No. Before Eton they lived on Chabot. But before Chabot, they lived next door to Loni Hancock's on Ward.

Bonney: And that's where the truck was parked? By the Ward Street residence?

Zukas: Yes. Eric was working for a while as my morning attendant, and he was open to getting an apartment with me.

Bonney: Where did you get an apartment?

Zukas: Dwight and Milvia.

Bonney: Up until this time were you living with your mother in her home?

Zukas: Yes.

Bonney: How did she feel about you moving out?

Zukas: She was supportive. She probably knew that she wouldn't be around forever. She hung around for a year and then she moved down to Pixley, where her mother lived.

Bonney: So you were really on your own after that first year. Mom was gone.

Zukas: She would come up periodically.

Bonney: How was living on your own for the first time?

Zukas: Okay.

Bonney: What was the best thing about it?

Zukas: Being able to control my own life. That was also the worst thing. Lately I have felt it as more and more burdensome, largely because of the difficulty in finding attendants.

Bonney: Would you want to go back to living in a situation where you were not on your own?

Zukas: That phrase covers a wide range. I would say yes, as long as it met my needs and desires, which is a huge qualification.

Bonney: Since you moved in with Eric and started living on your own, has the hardest thing always been getting attendants lined up and training them, et cetera?

Zukas: Yes.

Bonney: Is that the one thing that would drive you to a different living situation? That's the issue?

Zukas: There are times when I have to think and figure out what to have for dinner, and I don't like that.

Bonney: I'm with you there. [laughs]

Membership on Federal Architectural and Transportation Barriers
Compliance Board, 1980-1983

- Bonney: Hale, tell me how you got on to the Architectural and Transportation Barriers Compliance Board. You were appointed vice chair of the board, right?
- Zukas: One happened three and a half years before the other.
- Bonney: In other words, being appointed a member happened before becoming vice chair.
- Zukas: Yes.
- Bonney: Okay. Tell me how you got appointed to the board the first time around.
- Zukas: The board was established by Section 502 of the Rehab Act of '73 because there was dissatisfaction with the degree to which the Architectural Barriers Act, which had been passed in '68, was being complied with. Debbie and Ralf were going to get married in September of '77, and I was a little hurt that I didn't get an invitation. So I called them and told them I was going to drive back for the wedding. Ralf said, "Oh! Why don't you be my best man?" Anyway, when we arrived in Washington I went directly to the Washington Hilton where the board was having a meeting.
- Bonney: Were you a part of the board then?
- Zukas: No. End of digression.
- Bonney: Okay, so the board was meeting.
- Zukas: At the time, the members of the board were federal agencies; I think nine. When time came to reauthorize the Rehab Act in '78, there was still dissatisfaction with the degree of compliance with the Architectural Barriers Act. I think there were ten federal agencies. So in the '78 Rehab amendments, Congress added eleven public members. And Cranston offered to nominate Judy Heumann.
- ##
- Zukas: Judy, bless her heart, said he should nominate me, which he did. I think this was in early '79, and I mounted a letter-writing campaign. I pestered the board with several calls to find out what was going on. One of their staff members got in

trouble because someone used her name in a letter of support for me. Anyway, by July or August I had given up. In November there was a message that the White House had called. And I thought, Hmm, it looks like I'm still in the game. So I called them back and they asked what party I was registered in: Democrat or--. I lied. [laughter]

Bonney: You told them Democrat?

Zukas: I reregistered right away. [laughter]

Bonney: So were you appointed under Carter? Was he still in office?

Zukas: Yes. I had been registered in the Peace and Freedom party.

Bonney: That wasn't good enough for them? You think it would have hurt your chances if you had said you were other than Democrat?

Zukas: Probably not, but why lower my chances?

Bonney: Who was chair of the board when you first joined?

Zukas: Max Cleland, who was just elected to the Senate last November. But at that time he was administrator of the Veterans Administration.

Bonney: How did you become the vice chair?

Zukas: You're getting way ahead of the game. One of the provisions of the 1978 Rehab Amendments required the board to develop minimum guidelines and requirements for accessibility design.

Bonney: Accessibility design of what? Public buildings?

Zukas: Of federally owned buildings. At our first meeting in January of '80, the representative of HUD moved that we adopt the ANSI [American National Standards Institute] Standards as the minimum guidelines. I made a substitute motion that the board develop its own set.

Bonney: Did they take your motion?

Zukas: Yes. By the way, I was appointed to a one-year term. Since all public members were appointed at the same time, some were appointed to one-year terms, some to two years, some to three years. Well, I was disappointed at being given a one-year term. Before the end of the week of the election in November, I learned that I would be reappointed for a three-year term. The regular term was three years, but at the beginning--in

order to establish staggered terms--so some members were given one-year terms and some two-year terms. I've been told that I was given a one-year term so Carter would have an opportunity to reappoint me.

Bonney: So you were used as a little political ball.

Zukas: Yes.

Bonney: How did you feel about that?

Zukas: Nice. [laughter]

Bonney: Tell me a little bit, Hale, about what went on when your suggestion was adopted to rewrite standards. What happened there?

Zukas: I need to leave in ten minutes, and this is a long story.

Bonney: Okay. We can stop here.

[Interview 8: May 23, 1997] ##

Bonney: When we left off yesterday, Hale, we were talking about your activities on the Architectural and Transportation Barriers Compliance Board. You were going to start talking about your proposal for new standards and what happened around all of that.

Zukas: The board spent several months developing MGRAD--that's the Minimum Guidelines and Requirements for Accessible Design. Something like seven months. They put out a notice of proposed rulemaking toward the end of the summer and received comments. Then in November Reagan was elected, so it became a rush job to put out the final rule before he came into office. We had meetings in both December and January. Normally, we met every two months.

Bonney: Are these MGRADs that were developed a result of your counterproposal a year earlier to the ANSI standards?

Zukas: Yes. I suppose that substitute motion identified me as something of a heavyweight. When a committee structure was established before the March meeting, I was appointed to be chair of the transportation committee. During the late seventies there was a lot of controversy over whether the transportation needs of disabled people should be met by providing paratransit or by making fixed-route service accessible. Well, in November of '79 the Congressional Budget

Office put out a report written by one David Lewis saying that the needs should be met--after the HEW 504 regs were signed, HEW later issued guidelines for the other departments to follow in issuing their own 504 regs. And I think it was sometime in 1979 that DOT issued its 504 regs which required fixed-route transit to be made accessible. By the way, the American Public Transit Association [APTA] was unalterably opposed to making fixed-route transit accessible.

Bonney: The report that came out from DOT, that fixed-route should be accessible, was that the report written by David Lewis?

Zukas: No.

Bonney: No. Okay, we need to get back to him at some point.

Zukas: Those were the DOT's 504 regulations. They gave different modes of public transportation various deadlines of up to thirty years for systems like the New York subway. But New York was apoplectic, claiming that it would cost a billion dollars. So in November of '79, the CBO put out the David Lewis report which claimed that a fleet of 1,650 vans would be enough to meet the demand nationwide.

Bonney: Who are they kidding? [laughs]

##

Zukas: So that set the stage for a battle royal in the next session of Congress over the Cleveland Amendment, which would have allowed each locality to decide how it would meet the needs of disabled people--the so-called "local option." Kitty Cone spent much of 1980 lobbying Congress against the Cleveland Amendment. And Dennis Cannon wrote a little book of his own, answering the CBO report, and that report was published by the American Coalition of Citizens with Disabilities [ACCD]. And I wrote one of the nice points that Dennis made, that 1,650 vans amounted to six vans per SMSA [Standard Metropolitan Statistical Area].

Bonney: Who is Dennis Cannon?

Zukas: He is one of those weird things--a person with traumatic CP [cerebral palsy].

Bonney: So he's in the disability movement.

Zukas: Yes. He was a consultant to the Southern California Rapid Transit District. Then he went to work for the access board.

Sprecher: You mean what was then the ATBCB.

Zukas: Yes. He undoubtedly is the foremost authority on transportation for disabled people.

Bonney: Is he currently working in the field somewhere?

Zukas: He's still at the access board. And I need to call him.

Bonney: Hale, you need to clarify for me what the Cleveland Amendment was. What are you exactly referring to there?

Zukas: I think his first name was James Cleveland, a congressman from New Hampshire.

Bonney: Was the amendment the 1,650-van concept? What was the amendment? I lost that somewhere.

Zukas: Local option. To leave it to localities. And I wrote a paper for the ATBCB answering four main arguments that were made against fixed-route accessibility, and arguing that the best solution was to have both fixed-route and paratransit, which is what we got in the ADA.

Bonney: So it took until 1990 to get this accomplished. Did you participate in the APTA demonstrations, Hale?

Zukas: Yes, I was at a couple of APTA demonstrations and in several meetings.

Bonney: Did you blockade the buses in San Francisco in--when was it?-- '84 or '85?

Zukas: It was in '87. The lead organizer of those demonstrations was Marilyn Golden.

Bonney: You went to Denver, also?

Zukas: Where I had six different attendants in three days. I came back early. [laughter]

Bonney: How is a person sitting on the ATBCB board--how did they take the fact that you were out demonstrating against APTA?

Zukas: For one thing, the trip to Denver was in 1983, and I was merely a face in the crowd. I realize that we're now dealing with two trains of thought: one on transportation and one on the ATBCB. Should I finish on transportation?

Bonney: That's fine.

Zukas: What I was saying was that the lead organizer of the '87 demonstration was Marilyn Golden, who was also the main lobbyist on the transportation--

##

Bonney: We had just said that Marilyn Golden was the chief lobbyist for the transportation provisions of the ADA.

Zukas: We should recognize--no, I will leave that for later. There's another person named Jim Raggio, who in the late seventies was leading the fight for TransBus. Have you ever heard of TransBus?

Bonney: Is that the one that goes across the Bay Bridge?

Zukas: No.

Bonney: I don't know what it is then.

Zukas: It was more of a concept--a bus with a low floor and wide front doors.

Bonney: Sort of a prototype concept.

Zukas: General Motors had just come out with its new transit bus, and General Motors was very opposed to TransBus. One day in 1978, they brought one of their buses to Capitol Hill to demonstrate. That morning a group of us met with the chairman of GM and they gave a group of congressmen a tour. I raced down the street--their bus had the lift in the back door. So I went to a mid-block bus stop where buses could not pull in, and the designer of the lift had to get me off the curb. [laughs] But for all that, TransBus died. When the ATBCB was developing its ADA requirements for transit vehicles, who do you think was its general counsel? Jim Raggio. End of that digression.

We succeeded in beating off the Cleveland Amendment, but DOT under Reagan repealed its 504 regs and replaced them with a requirement that transit operators spend either 3 percent of their operating budget or 5 percent of their federal funds on services for disabled people.

Bonney: Now whose rule was that? Who said that?

Zukas: This was the DOT that replaced the 504 regs with this requirement, under Reagan. In '82, I think Congress passed a

provision introduced by Cranston which brought in Dennis Cannon's service criteria. DOT issued new regulations which addressed those, but I don't remember how, and then ADAPT sued against them and won in '87 in Philadelphia at the appeals court. At this point, APTA for some reason abandoned its fight against accessible fixed-route transit. There was not much of a fight over that when the ADA was being considered. I was chair of the Board Transportation Committee during this time, from 1980 to '83--during the darkest time. One more thing about transportation: a couple of months ago, the AC [Alameda-Contra Costa County] Transit Board decided to get some low-floor buses which are now being made.

Bonney: So the TransBus is coming back. [laughter]

You were going to mention something about Marilyn Golden, and then you said you would do that later. What about Marilyn?

Zukas: No. What I was going to say later is APTA giving up.

Bonney: Okay. Can we go back and talk a little bit more about the ATBCB for a second?

Zukas: Yes.

Bonney: How did you become that vice chair? When did that happen?

Zukas: Now I'll go back to my other train of thought. You asked me why some people did not want to use ANSI. Well--

##

Zukas: At that point, ANSI was very sketchy. It was only twenty pages long. Although in April 1980, a new, much more detailed version was published. But the feeling was that it was not restrictive enough. Also, ANSI does not have any scoping provisions; it only sets forth the requirement a bathroom, for example, has to meet in order to be accessible. It doesn't say which bathrooms have to be accessible.

Bonney: You hoped with your counterproposal to put tougher standards in place?

Zukas: Yes.

Bonney: Were you successful in doing that?

Zukas: Yes. The opponents said we were only supposed to issue minimum guidelines and requirements, not standards.

Bonney: Who were the opponents?

Zukas: The leading opponent was the Postal Service. [laughter] I believe the final rule issuing MGRAD was published on January 19, 1981, the last day of the Carter administration.

Bonney: So you all made it. You made the deadline. Before noon, I assume. [chuckles]

Zukas: For the next year and a half we fought over whether to rescind MGRAD.

Bonney: And the decision was?

Zukas: In July of '81, the ten federal members and one renegade--a public member--voted to rescind.

Bonney: So then you went back to using the revised ANSI?

Zukas: Have you ever heard of working to rule as a labor tactic?

Bonney: No.

Zukas: In some situations, unions would not strike; they would just insist on doing everything by the rule. Every year the chairpersonship rotates between federal members and public members, so during '81 the chair was a loud lawyer from L.A. who was definitely not the renegade. So after the vote to rescind the guidelines, the board staff connived with the chair to delay by doing everything by the rules. After the NPRM [Notice of Proposed Rule Making] was finally published in September or October of '81, they quietly orchestrated a campaign to continue to generate outrage in the disabled community.

A digression. At least at the time there were four federal standard-setting agencies. One of them is the General Services Administration [GSA]. The commissioner of the Public Building Service at GSA was named David Dibner. Does that ring a bell?

Bonney: Related to Eric?

Zukas: A cousin who I had met in 1980.

I engaged in some shuttle diplomacy during the first half of '81, trying to persuade David Dibner not to vote to rescind the guidelines.

Bonney: Did it work?

Zukas: No. But he did come up with the idea of a Uniform Federal Accessibility Standard, or UFAS.

[Interview 9: May 27, 1997] ##

Bonney: Hale, we're going to continue talking about your involvement with the Architectural and Transportation Barriers Compliance Board. Can you tell me how you become appointed as vice chair?

Zukas: At the end of the last session, I was talking about the board finally issuing an NPRM--that's a Notice of Proposed Rule Making--around September of 1981 proposing to rescind MGRAD. The board chair, with the quiet connivance of staff, orchestrated an outcry among the disabled community which generated hundreds of comments saying MGRAD should not be rescinded. Meanwhile, you may recall that Reagan was having a hell of a time finding someone to be assistant attorney general for civil rights. Well, he finally did find William Bradford Reynolds. The people who represent federal agencies on the board are usually assistant secretaries, which in the case of the Department of Justice is the assistant attorney general for civil rights.

Bonney: So Reynolds served on the board then.

Zukas: While he was horrible on most issues, actually he was very interested in promoting accessibility. He became an advocate of MGRAD. Now, my memory of '82 is hazier than of '81, but I know that in early 1982 we withdrew the rescission of MGRAD. Sometime later, we asked for suggestions for changes in MGRAD. The board had an executive committee which was made up of the chair and vice chair of the board along with the committee chairs. So being chair of the transportation committee, I was on the executive committee. I developed a pretty good relationship with Brad Reynolds. The fight over whether to rescind MGRAD had produced a real schism--well, a polarization --among the board. I don't know whose idea it was to try to bring the two sides closer together, but eventually someone had the idea of having a retreat, and I was assigned the job of finding a place. So in January Dennis Cannon drove us to look at two or three places, and I remember one Thursday night we were driving back from Williamsburg and it began to snow. The beginning of one of the worst blizzards in the decade.

##

Zukas: The way I got back was by taking a train to Newark, New Jersey, where my uncle put me on a plane to get back here.

Then in March my mother and I rented a car, and we looked at some more places. At the May meeting I made my recommendation of where to hold the retreat. I should say that Brad Reynolds was elected chair of the board in May of '82.

Bonney: Are we now into May of '83 when you're recommending where to hold the retreat?

Zukas: Yes. One night in late '82 I called Brad's office when I was here alone. I don't remember why, but he answered [laughter] and I was very flustered. He handled it very well. Anyway, in May '83 the next election came up. By then I was one of the most respected public members. [To Sprecher] Do you remember whether there was the possibility of me running for chair?

Sprecher: I think there might have been. I'm not sure. I think I might have argued against your doing it. I don't know if it was then or some other time.

Zukas: I think none of the public members either were interested or was chairperson timber. So what finally transpired was that Brad ran for chair and I ran for vice-chair against a quad who was a real lightweight. [laughter]

Bonney: Who was he?

Zukas: Scott Duncan. He got Bush to appoint him again, and I hear he usually didn't show up.

Bonney: Okay, so let me recap for a second. I think we've done it. You became vice chair of the board in May of '83, and you were vice chair for how long?

Zukas: Until my term expired in December '83. Let me tell you about perhaps the single most surreal period of my life. I should say that members of the board could give their proxy to other members, and Brad had five or six proxies. The night of the board meeting I was elected vice chair, I turned on Nightline, and it was a debate on affirmative action. And who were the debaters? Brad Reynolds and Joe Califano. [laughter]

Anyway, the board decided to have its retreat at the Bedford Springs Hotel in Pennsylvania, and Roger Craig, the Postal Union guy--our fiercest nemesis in the fight over MGRAD --rented a van to give me a ride up from Washington. Then after the retreat Dennis Cannon gave us a ride to Cumberland where we got a train to Pittsburgh. Remember I said one of the two times I stayed up all night was when I was watching an engine being put in a van?

Bonney: Yes.

Zukas: That van belonged to one of my attendants who drove back to Indiana. He was going to meet me in Pittsburgh and drive back with me. First he called and asked if I could wire him some more money. I had already put close to \$1,000 into this project. So Nina [Sprecher] got on the bus and went to Detroit, and then this guy called and said he was not coming.

##

Zukas: Well, there I was, stranded in Pittsburgh. For some reason, I couldn't fly back from Pittsburgh. So I got up at three o'clock in the morning--after going to bed very late and lying awake most of that time--and got back on a train to Washington. Bruce arranged for someone to pick me up and take me to the airport.

Bonney: Bruce who?

Zukas: Baker.

Bonney: Was he a friend? An attendant?

Zukas: I guess it was May '81 when I got a call in my hotel from this guy, Bruce Baker, who was at the annual meeting of the President's Committee. He said he wanted to meet me. He talked about his idea for communication strategy.

He spent several years trying to sell me on this communication strategy, driving me around Maryland and western Pennsylvania, and even once to Barry Romich's place in Ohio. Now there are some people who just get under my skin, and Bruce was one. You could say our relationship was rather pathological, with him keeping wooing me, and me keeping spurning him, often in no uncertain terms.

Anyway, Bruce sold Prentke-Romich on his idea, and the Liberator, their top-of-the-line augmentative communication device which you have probably come across, is built around it.

Urban Institute National Study

Bonney: Let's go back in time to the early seventies when you were at CIL. At one point you were involved with something called an Urban Institute National Study--I think of the needs of people

with disabilities. Can you tell me about what that was and what you did?

Zukas: The Urban Institute had a big contract to do a needs assessment. One of the tasks was to do a literature review, and they subcontracted with CIL to do it.

Bonney: It was a needs assessment of what?

Zukas: The disabled community.

Bonney: Were you in charge of this project?

Zukas: I think Ken Stein and I did the part on accessibility.

Bonney: How were the results of the study used?

Zukas: I can't say.

Bonney: What were the major issues that you included in your research? What areas did you cover?

Zukas: Accessibility. Both architectural and transportation.

Bonney: Was there more to the study? You said that you were in charge of this part of it. Did it include other things too?

Zukas: Yes. There were other topics in the literature review. And the literature review was only part of the larger study.

Bonney: So you worked only on the literature review in access in transportation. Is that right?

Zukas: Yes.

Bonney: Can you give me some examples of what issues came up that you found as you went to do the literature review?

Zukas: It was my first experience with computer searches. My only recollection is that most of the stuff we found was pretty useless. But there were a few things that were really good.

Bonney: Why were most things useless? What was wrong with them?

Zukas: I thought I was doing well to remember that much. [laughter]

Bonney: What I was wondering, Hale, is if you felt like it was useless information because people at that point didn't understand disability, or everything was geared toward the medical model

or they just plain had never thought about access for people with disabilities, or if there just wasn't much written at that point. What are your thoughts about why most of it was pretty useless?

Zukas: The word that comes to mind is pedestrian. My recollection, dim though it is, is that most of the stuff was looking at things I considered relatively insignificant.

Working to Make Bay Area Rapid Transit Accessible, 1975-1977

Bonney: At some point you got involved with BART [Bay Area Rapid Transit]. Can you tell me what your impetus was for getting involved with BART and its access issues?

Zukas: A few of us, Phil Draper and I--and I don't know who else--were invited to take a tour of BART in September '72. And MTC [Metropolitan Transportation Commission] funded a BART impact study sometime around '74.

Bonney: Now this was after BART was built and running?

Zukas: Yes.

##

Zukas: The first segment was MacArthur [Station] to Fremont. My recollection was in June '72, but now I remember they were having their twenty-fifth anniversary some time ago, so that can't be right. Anyway, different lines opened up at different times. I started going to meetings of what is now the BART Accessibility Task Force in '75. I must say most of the progress BART has made becoming more accessible has been in response not to the task force but in response to lawsuits.

Bonney: Way back when, you wrote a paper on why people with disabilities were not riding BART. What did you do with that paper after you wrote it?

Zukas: I think the immediate reason for writing that was that DOT was having some kind of hearing. People were pointing to the low disabled ridership as an argument for not making it fixed-route accessible.

Bonney: So you wrote the paper, and I assume BART read it and/or presented it to DOT.

Zukas: No, I did.

Bonney: Did BART take it to heart? Did they start doing things because of it?

Zukas: The accessibility problems with BART were only a small part of that paper. And many of those were because it was incomplete. The main thrust of the paper was that mobility is a learned skill.

Bonney: You mentioned that most of their progress on disability issues came through lawsuits. What did people have to sue over to get changes?

Zukas: One lawsuit was over the elevators. Until the mid- to late eighties, only the station agent could operate the elevators. Lesley Levy sued them over that and they agreed to spend a couple of million to install push buttons.

Bonney: Hale, when BART gets a lawsuit like that, does the board or task force play any role in resolving it?

Zukas: No. You mean are we part of the negotiations?

Bonney: I mean are you told about the lawsuits, are you told what the issues are or anything like that? Are you able to make any recommendations to BART on resolution?

Zukas: BART is being sued yet again over accessibility, and some time ago within the last year, one of the outside lawyers talked to the task force but I can't remember why. Jean Nandi has organized an outside pressure group called the Access BART Coalition, and that has had an effect.

Bonney: A positive effect on BART?

Zukas: There are now a number of signs at the agent booth, outside the elevators and in the elevators, listing which elevators are out of service.

Bonney: Was that because of the Access BART Coalition?

Zukas: Yes.

Bonney: Hale, with all the years that you've worked with BART--and I understand you still are. Is that right?

Zukas: Yes.

Bonney: What has been your most satisfying accomplishment? Or what do you feel best about, having influence with BART?

Zukas: I said the task force has not been involved in the various lawsuits. By the way, another lawsuit was brought by visually impaired people because some people had fallen off the platform. So it is in response to that that they put what are known as truncated domes on the edge of the platform. Anyway, the task force has been involved in arriving at solutions which would be used to settle the lawsuit. And I guess I am proudest of my role in locating the buttons by the elevators and helping with the signage that is mandated by the ADA.

One of Jean Nandi's accomplishments is that there's going to be a so-called disability summit with members of the BART board on June 14.

Bonney: Is Jean on the BART board? Or what is she?

Zukas: I first heard of her as a harpsichordist, but she has become much more disabled. Probably no less active, she is chair of the Berkeley Commission on Disability.

IV PURSUIT OF PERSONAL INTERESTS, POWER AS A LEADER, AND VARIOUS OBSERVATIONS

Discussion of Ed Roberts

[Interview 10: May 28, 1997] ##

- Bonney: Hale, many weeks ago when we were talking about the early years in CIL, you were telling about how a group of you would meet at the old PDSP and talk about what a CIL would be and what kind of services it should provide and how you were going to start, et cetera. You mentioned at that time that Ed Roberts and Judy Heumann were not part of those early-on discussions. Can you tell me when Ed came into the picture and what he did?
- Zukas: I don't think he became involved until CIL moved to University Avenue.
- Bonney: And that was about what year?
- Zukas: In 1973 or '74.
- Bonney: So CIL was established at that point and had its first grant?
- Zukas: Oh, yes.
- Bonney: And what did Ed do when he came in? What was his role?
- Zukas: At some point he became executive director, and I think he was on the board for a brief period before that.
- Bonney: How did it come about that Ed was executive director? How did that happen?
- 4

- Zukas: Well, Larry Biscamp left--I don't remember why--and I have a vague recollection Dick Santos was acting executive director for a time.
- Bonney: After Larry Biscamp and before Ed?
- Zukas: Yes.
- Bonney: What things did you observe Ed doing?
- Zukas: What do you mean?
- Bonney: Was he developing public policy? Was he speaking to legislators? Was he organizing? Was he writing reports? What kinds of things was Ed doing as the executive director--that you observed him doing?
- Zukas: He got a lot of grants and CIL grew very fast. Too fast, in fact. I don't think any thought was given as to how grants fit into the overall structure.
- Bonney: What did you see happen to CIL as it grew, in your opinion, too fast? How did it manifest itself?
- Zukas: It became very unwieldy and hard to manage.
- Bonney: What kind of a manager was Ed?
- Zukas: Not good. Ed's strength was his rhetoric and charisma, I guess, although I never found him charismatic. This may be somewhat heretical: for all his great gift of gab, I found him rather superficial. Well, a few years ago there was an intern at WID whom Ed and I were supposed to share responsibility mentoring. I didn't do a very good job, but then I could say I didn't have any experience, but Ed had been a teacher, and he did very little. I resented it. I supposed I seized upon it as exemplifying his overblown reputation.
- Bonney: Did you and Ed have words over this incident?
- Zukas: Yes. Once I took him to task for not following through on his commitment. [To Sprecher] Do you remember?
- Sprecher: I have vague memories.
- Bonney: What was Ed's response?
- Zukas: What I remember is that he acknowledged that he had failed.

Bonney: Do you remember who the intern was?

Zukas: Oh, yes. Aidan Aysoy.

Bonney: We'll check the spelling later.

Ed Roberts and Judy Heumann, usually in the same breath, are credited with being the co-founders of CIL.

Zukas: Yes, well--

Bonney: What do you think of that statement?

Zukas: That's another example of Ed's overblown reputation. I'm not aware of Judy being described that way nearly as much. I will acknowledge that in recoiling from Ed's overblown reputation I may have--

##

Zukas: --gone too far in the other direction. After all, my first trip to Death Valley was in his van. I added 50 percent to the mileage on that van.

Bonney: You mean you used his van frequently for things?

Zukas: Yes, and one day in '75 Karen Topp came into my office and said, "Your van is going to be here Friday."

Bonney: Did you know she had made arrangements for you to have a van?

Zukas: No.

Bonney: Wow. Karen did that without even working with you? She just did it?

Zukas: That was shortly after Ed had become director of Rehab.

Bonney: Hale, if Ed's reputation was sort of overblown and he was taking credit for things that you feel he really didn't deserve credit for, why did the people with disabilities who were working at CIL allow him to take the credit for what other people had done?

Zukas: You say "the people at CIL." Who?

Bonney: I don't know. You said that you felt that his reputation was overblown, and that he took credit for being the founder or co-founder of CIL. You said you felt sort of resentful of that

position, that he allowed himself to bask in that glory when it wasn't really true. Were there other people at CIL that felt that way? If so, why did you let that happen?

Zukas: Several points. I don't think that I became resentful until the late seventies or early eighties. By then, most of the people who would know what had gone on in the early days were gone. And further, a lot of the people had sort of grown up with Ed in a sense. Then by the late seventies and eighties Ed had become an icon. Even if people were inclined to think that the emperor had no clothes, it would have taken some courage to say.

Bonney: What triggered your realization of your resentment in, say, the early eighties? Did something happen?

Zukas: I guess hearing a lot that he was the founder of CIL and getting the MacArthur Award. When I heard a few years later that Ralf Hotchkiss got one, what popped into my head was something like, "Finally, someone who deserves it got it."

Bonney: Hale, do you think in the early seventies when CIL was being developed and you all were sort of doing your work and the independent living movement was gathering momentum, do you think that the movement needed someone like an Ed Roberts at that time to make the movement sort of catch on and be nurtured?

Zukas: Probably. It is undeniable that Ed planted some seeds. It was not long after he became director of Rehab that he gave out a number of grants--I think seven or eight around the state for the establishment of ILC's. Then [Assemblyman] Tom Bates--whom I saw Sunday at this report back on the Wheeled Mobility Center [Open House]--introduced AB [Assembly Bill] 204. Anyway, AB 204 established ongoing funding for ILC's [Independent Living Centers] in California.

Bonney: Did you ever see Ed Roberts give credit to someone for work that they had done?

Zukas: I'm sure, although I can't remember anything now.

Future Issues in Independent Living

Bonney: What do you see as future issues in the independent living movement? What's ahead for us?

- Zukas: Continuing to fight for things that enable disabled people to live independently, as trite as that may sound.
- Bonney: You think there are some specific hotspots that we're going to run up against?
- Zukas: What do you mean?
- Bonney: Do you think that there are particular issues that you see coming up that are going to be really important and hot issues?
- Zukas: The need for PAS [personal assistance services]. There are probably more, but I can't think of them.
- Bonney: In the seventies, and probably up until about 1990, I think it was a very exciting time--
- ##
- Bonney: I was asking you a question when we ran out of tape. The seventies and eighties seemed to be an exciting time for people with disabilities. You were going through the experience of being on the Architectural and Transportation Barriers Compliance Board, we were in Washington, we were working on things, we were sitting in, we were demonstrating, we were being heard and being recognized, and stuff was happening. Do you think it's as exciting nowadays as it was then?
- Zukas: No. I feel a real loss when I don't have something to pay my way to Washington every so often. [laughter] So I applied to be on another committee. But seriously, there does seem to be less interest in political advocacy.
- Bonney: What do you wish was happening now that would liven things up? If you could just have anything to make things lively and interesting again, what would you like to see happen?
- Zukas: I was afraid this would happen, that you would ask hard questions. Okay, what I wish is that there was an energized cadre of disabled people out there who were chomping at the bit to write letters to the legislators. That probably applies to me.
- Bonney: Why do you think there isn't this cadre out there?
- Zukas: Two things. One, there are no real threats. And two, they're not organized.
- Bonney: Whose job is it to develop new leaders and organize them?

Zukas: Their leaders--ha ha. [laughter] That's not entirely facetious, in that advocacy groups should be continually bringing in new blood. Going back to your question about why there are so few active disabled: they don't feel they can make a difference. On Monday I gave Simi [Linton] a bunch of materials asking people to lobby their representatives and senators against cuts in Medicaid. I wrote a note saying I had virtually no energy for this, when we will just be a peep in the roar of the crowd.

Bonney: Why don't you have any energy to do it?

Zukas: I guess I'm just too tired.

Personal Observations

Bonney: Are you bored with the world at this point?

Zukas: A lot of the time, yes. Exactly.

Bonney: Are you tired of being a leader in the disabled movement? Or are you tired of being a role model or tired of being the constant spokesperson on certain issues? What's gotten to you, as someone who has worked twenty-five years in the area?

Zukas: Well, I was going to say I don't consider myself a leader, but I guess I am one in certain contexts. After all, I do feel qualified to be on some national committees, and I guess that makes me something of a leader. As far as being a role model goes, that really gives me the heebie-jeebies. I think I have no business being a role model. Maybe I should say I feel I have no business being a role model.

Bonney: So what has you bored and tired? What is it?

##

Zukas: The difficulty I'm having in finding attendants probably has something to do with it, life being more a struggle as time goes on.

Bonney: Evidently you were the subject of a cartoon in the Oakland Tribune. Could you tell me a bit about it?

Zukas: That's one of the more interesting stories. On the morning of my forty-eighth birthday, I was sitting on the toilet, and

Roberta Brooks of Congressman [Ronald V.] Dellums' office called to say I had been chosen as the first recipient of the Florence and Worden McDonald Award for Community Service, which carried with it \$1,000. I was a little worried about it affecting my SSI. So later that day I went to Marion's [Conning] office to see if WID could hold it. I said I had been chosen. And she brought out the letter she had written, nominating me. Anyway, there was a flurry of publicity around that.

Bonney: And the cartoon came out in response to that?

Zukas: Yes.

Bonney: It wasn't Doonesbury, was it?

Zukas: Wee Pals.

Bonney: And the date on that was March 1, 1992?

Zukas: Yes.

Bonney: So did you get to keep the \$1,000?

Zukas: Well, WID still has it. [laughter]

Bonney: Maybe. [laughter]

Hale, I want to thank you very much for letting me come and interview all these weeks, and you've been gracious to let me into your home. You've been candid and you've been honest, and I really appreciate it. Thank you very much.

More on Early Teachers

[Interview 11: January 5, 1998] ##

Bonney: Hale, earlier on in your interview you talked about your teacher--I believe the first teacher you had at the Jespersen School--and you have a picture of her up on your wall working with you.

Zukas: Well, she was not the first. Martha Bromley came--I think it's '49. The teacher in my first year was nothing special.

Bonney: So she was your second teacher?

- Zukas: Yes.
- Bonney: And her name was Martha Bromley?
- Zukas: Yes.
- Bonney: You mentioned that you had seen her recently. Have you carried on a long-term relationship with her?
- Zukas: Yes. Until a few years ago they lived about three blocks from the Millers, who were the downstairs neighbors when we moved into that old Victorian. And we always stay with them when we go down south.
- Bonney: Tell me about your last visit with your teacher Mrs. Bromley.
- Zukas: Three or four years ago they moved to a complex for retired air force personnel near Riverside. We drove about fifty miles from Orange to visit them.
- Bonney: What's your relationship with her like?
- Zukas: I just called Helen a half an hour ago to ask why we have maintained contact with them, and she said, "Well, we like them and they like us," which is essentially the answer I came up with.
- Bonney: When you're with Mrs. Bromley are you still the student and she's the teacher? Or is your relationship a little different?
- Zukas: No. I would like to know what it would be like if I were still the student in your mind.
- Bonney: I was just wondering if you've grown up in her mind or not, because a lot of times we don't. [chuckles]
- Zukas: Another thing that Helen said was that she and Sally Twigg, who was the occupational therapist at Redwood City and who got the idea of my typing with my foot and later with my head, were rare in that they respected me.
- Bonney: Did they work together, these two teachers?
- Zukas: No. Martha Bromley was in San Luis Obispo and Sally Twigg was in San Bruno.
- Bonney: But they didn't collaborate with each other or talk--

Zukas: No. It happens that they both came for the presentation of the McDonald Award.

Bonney: Oh, they came to Berkeley?

Zukas: Oakland.

Love of Trains and Bridges

Bonney: Hale, you also said earlier on that when you were children your father took you and your brother and sister to the library on Saturdays. What else did you do with your father?

Zukas: Go out for rides. And before leaving L.A. we would go out to watch the trains.

Bonney: And where was that?

Zukas: In East Los Angeles.

Bonney: Are you a train lover?

Zukas: Yes.

Bonney: How did you get interested in trains, and what's so fascinating about them?

Zukas: I don't know. I can remember going to the roundhouse in San Luis Obispo. I guess I just learned that they were something special.

Bonney: What do you do with trains now?

Zukas: I like to follow trains with steam engines and take pictures.

Bonney: What do you mean "follow"? You mean literally follow them down the tracks or just follow their history?

Zukas: Drive along the tracks.

Bonney: While the train's going on the tracks?

Zukas: More or less along the tracks.

Bonney: Can you do that very often? I mean, I don't know about steam trains. How often does one get to do that?

- Zukas: Not often. There is a restored locomotive and train painted in the orange and red Daylight scheme. There used to be the Coast Daylight and the San Joaquin Daylight going between San Francisco and L.A.
- Bonney: Did you ride on these trains?
- Zukas: Helen and I went home once from Redwood City--
- Bonney: When you were a child?
- Zukas: Yes.
- Bonney: You haven't taken any train trips as an adult?
- Zukas: Oh, yes. I took one in '69 or thereabouts up to Portola, through the Feather River canyon. And then another in 1970, a week before it was discontinued.
- Bonney: The Portola trip? That was a week before?
- Zukas: Yes. There is nothing in Portola. I couldn't get tickets back, so we had to take the bus. And then in '74 Eric and I--
- ##
- Zukas: Then in 1974 Eric Dibner and I went to a conference in Denver. We rented a VW Beetle, which I hear is being built again for \$16,000. We drove around Colorado for a couple of days. And we were going to fly back. Maybe we were going to take a train to Salt Lake City and then fly back. Anyway, I got to thinking about it and thought, "Why not? What about taking the train from Ogden [Utah]?" So we decided to do that. We rode in the Vistadome from Denver to Salt Lake, which was another great ride.
- Bonney: How did you get up in the Vistadome?
- Zukas: Eric or my cousin Jonathan would carry me. One of the train crew may have helped. But for that matter, getting me up in the Vistadome was easier than getting on the train itself, probably.
- Bonney: Why was it easier? What did you have to do to get on the train?
- Zukas: Get carried on and off.

Bonney: Now Hale, there's this story that Kitty tells in her transcript--

Zukas: Well, you got me started, so--. So we get to Salt Lake, and there were not that many people going to Ogden, so they used a Chevrolet Suburban to take us the thirty or forty miles to Ogden, where we got a sleeping car. The next morning Eric pulled up the shade and said, "Well, we just went through Gerlach." And I said, "What??" because Gerlach was on the Union Pacific, which goes down the Feather River, and we were supposed to be on the Southern Pacific, which goes over the Donner Pass.

Bonney: The one you were on or the one you were supposed to be on?

Zukas: The train we were on was supposed to go over the Donner Pass. But when Eric said that we just went through Gerlach, I saw that we were going down the Feather River. I was almost out of film. [laughter] When we stopped in Portola Eric got out to look for film.

Bonney: And the train took off? [laughter]

Zukas: He got back in time, but still that was not very smart. And then about three years ago my attendant and I--they had a series of excursions up and down the Feather River. One of my attendants drove us to Oroville, and then we got on the train. We took the train to Portola and rode a bus back.

Bonney: It sounds like all trains lead to Portola. [laughter]

Sprecher: Well, some lead to Sacramento, but those aren't the pleasure trips. Right, Hale?

Zukas: Yes.

Sprecher: He's taken a lot of trips on the train to Sacramento.

Zukas: And in '96 I got up at four one morning so we could catch another excursion to Portola, only to get up there and find it had been canceled. We were going to go to Fremont instead.

Bonney: I was going to ask you about another train incident here. Kitty says in her transcript that she and Joan Leon needed to have a meeting with you one day. Are you remembering this sort of? I see a smile. [laughs] You said you could meet with them but you had to meet down on the edge of the railroad tracks in the city of Berkeley because a special train was coming through. Can you tell me about that incident?

- Zukas: Yes. The Daylight was going from Sacramento to Oakland.
- Bonney: And why was that a significant thing that you needed to see?
- Zukas: It was one of those trains from the fifties--that restored train that I talked about.
- Bonney: Oh, the red and orange Daylight. Okay. Kitty also tells a story about another of your interests, I think. She said that you and she and someone else were driving to Sacramento and the other person was blind--I can't remember who it was now--and that when you went under bridge overpasses the blind man took pictures of it for you. [laughter] What's your interest in the overpasses on bridges?
- Zukas: I don't know, except ever since I can remember I've been very interested in highway construction, and later in bridges. You see that calendar?
- Bonney: Yes, the bridges calendar. What do you like about bridges? What interests you?
- Zukas: I can't explain. And not being able to explain, I am beginning to question my interests.
- Bonney: Oh, you shouldn't do that. You like looking at bridges, they're beautiful. Is it the technical aspects of how they're built that you like to look at, or just the beauty of a bridge? Like the one we're looking at in the calendar is a very beautiful, brick, ornate structure.
- Zukas: The beauty.
- Bonney: Do you have other interests, Hale, besides trains and bridges and highways?
- ##
- Bonney: You had just said that politics is an interest of yours. Are there other things that you follow or like to do?
- Zukas: Current events, science, travel, and photography. The phrase that comes to mind is jack of all trades and master of none.
- Bonney: Okay, so you have a general interest in lots of things.

Let's go back just a little bit to your high school years. Can you tell me what interests or activities did you

participate in in high school? Or did you participate in extracurricular things?

Zukas: No, except for going to a few football games.

Bonney: Were the courses that you took in high school college prep? Were you planning on going into college?

Zukas: I think they were college prep, yes.

Parents' Expectations

Bonney: How did your parents' view of you and their expectations for you as their child with a disability shape who you became or how you dealt with your disability?

Zukas: It has shaped me for both good and ill. I see myself as a mass of contradictions. On the one hand, I'm very activist in trying to influence various issues, sometimes being very assertive about it. On the other hand I have very low self-esteem, and I don't like to deal with employment issues at all. Probably because I don't see myself getting a job.

Bonney: How did your parents instill this assertiveness in you and this power that you have? What did they do to bring that out in you?

Zukas: For one, Helen fought to get me in regular school. There were probably other lesser battles that I don't remember.

Bonney: What were your parents' expectations for you?

Zukas: Well, the answer I feel like giving is "ask Helen."

Bonney: But what did you think their expectations were? For instance, did they think that you would go to college, that you would be independent, that you would live on your own, or was the expectation that you would probably stay in the home?

Zukas: The expectations were that I would go to college. I said some time ago that in '54 people concluded that my intellectual ability was my most valuable asset--perhaps my only valuable asset.

Bonney: You said that your parents' expectations shaped you good and bad. And you mentioned as a bad that you have low self-esteem. What happened to create that feeling?

Zukas: Helen pushing me so hard to exercise.

Bonney: What about that, that has given you low self-esteem?

Zukas: It is called internalized oppression.

Bonney: Have you had counseling to work through this?

Zukas: I've had three periods of going to counselors, and each time I decided I wasn't getting much out of it.

Bonney: What do you think of the ability of the medical professionals to work with people with chronic disabilities?

Zukas: I have had very little contact with medical personnel in the last thirty-five years.

Bonney: But you said you were going through some counseling sessions for this internalized oppression, and you weren't getting anywhere with them. Why was that?

Zukas: The best answer is that I didn't feel they were getting to my problem. I know that's not a very good answer.

Bonney: Do you think they weren't getting to the problem because of disability issues? That they don't "get it," in a way?

Zukas: The first guy was in a wheelchair, although I don't know how long he had been using a wheelchair. I would think that people who have been disabled since birth would be better adjusted to it than people who have become disabled later, but it seems the reverse, and it rankles me.

##

Zukas: Periodically Nina pushes me about getting counseling, but I see it as being like looking for a needle in a haystack.

Views of the Ideal Job

Bonney: Let's go back to one other thing that you mentioned just now. You mentioned that you never had a job. That sounds like an

odd statement to me from someone who has done as much as you have. Can you explain what you mean?

Zukas: I didn't say that I've never had a job. I said I don't see myself as getting a job.

Bonney: I guess what I need to know is what your definition of a job is. Because right now you're working at WID and maybe other places I'm not aware of. What do you consider a job?

Zukas: Something where you're doing a task and you're held accountable. I'm scared of being held accountable. Like WID was supposed to put out a paper on best practices last May. It is now in my lap, and I'm not very clear about what to do with it. So I'm afraid of working on it, and I'm afraid of not working on it. I often find that once I get into something it's not as bad as I expected. But knowing that doesn't change the feeling--well, maybe it does but not by much.

Bonney: What would be your ideal job for you?

Zukas: Where I was paid lots of money for doing stuff that was well within my capability.

Bonney: And are you afraid that you'll never have that job? Is that what you were saying?

Zukas: Yes. Well, I think "afraid" is too optimistic a word, because it implies a possibility.

Bonney: And you don't feel there's a possibility of this happening?

Zukas: No.

Bonney: Hale, "best practices" of what?

Zukas: Personal assistance services. Although at least one of the programs being described does not provide personal assistance.

Bonney: Okay. Let's switch gears a little bit. In another interview earlier on, you said that under some contexts you're afraid you're a conservative, and that you don't like labeling yourself that way but you think that's what you are. Under what contexts are you a conservative?

Zukas: Well, I'm more inclined toward working within the system than are some people. So I may be inclined to work through the proper channels, where other people might want to engage in disruptive actions. That makes me less pure in some sense.

Bonney: Several times you alluded to Tom Joe, who was in Washington, and you said you were writing a proposal for him, but we never really talked about what the proposal was. Can we clarify that?

Zukas: This was in the spring of '72, when CIL was still a desk at PDSP. Tom Joe was supposed to come out in the next week or so, and the proposal was laying out ideas for what we thought CIL should be, and asking for funding.

Bonney: Did that proposal go in to Tom Joe in Washington?

Zukas: Yes. But nothing came out of it.

Bonney: So it was not a proposal that helped fund CIL or get it started.

Zukas: No.

Bonney: What department was it written to?

Zukas: HEW.

Burning Draft Card

Bonney: Hale, why did you want to burn your draft card?

Zukas: To show my resistance to the Vietnam War.

Bonney: Did you burn your card?

Zukas: Well, what do you mean did I burn it? Did I? Actually, no; I gave it to a neighbor who took it to a rally where it was burnt.

Bonney: Did you attend the rally?

Zukas: No, believe it or not.

Bonney: Why didn't you go?

Zukas: I don't know. But as I recall, I didn't feel a pressing need to go, which I find sort of inexplicable now. My guess is that it was complicated getting me there.

Bonney: Did you get in trouble with the draft board for doing that?

- Zukas: Yes, that was when they reclassified me 1A.
- Bonney: Oh, that's what caused it. They didn't know anything about you; they just knew you burned your draft card.
- Zukas: Yes.

Power as a Disability Rights Leader

[Interview 12: January 12, 1998] ##

- Bonney: Hale, I want to talk today a little bit about the power that you have as a disability rights leader. It's very clear from your disability that you have severe speech involvement and that you frequently use an interpreter such as Nina. But when you're in public settings or meeting with officials or legislators they listen to you, and they listen very carefully to you. How do you make people listen to you?
- Zukas: Several caveats: when I'm talking it is usually in one-on-one situations, and basically there is no alternative, so I guess I don't understand your question, which implies there is an alternative. Usually I'm either in a one-on-one situation or in a hearing when I'm the only one speaking. And in most hearings I have written out what I want to say, and someone reads it. That said, I guess there are two things I do. One is that I don't beat around the bush. I'm very plain spoken. My statement at the Bay Bridge meeting was an example. Another thing is that I sometimes make it clear I know at least as much as anyone about what I'm talking about. An example was Friday when a group of us went to Fremont to meet with Assemblywoman Liz Figueroa. I talked about what the funding split for the IHSS program was. I was there as a member of the Public Authority Advisory Board. I felt I needed to go because Mark Beckwith, who is also pretty sharp, was sick.
- Bonney: Hale, what was the Bay Bridge meeting example? What happened at that meeting?
- Zukas: Back in November--well, I had meant to write it down beforehand, but fortunately Jonathan Marsh was there. By the way, that is where I need to go today, to the latest round in our years-long battle to get the region's transit operators to accept SSI status as eligibility for a regional transit discount card. Three times, the Regional Transit Coordinating Council Accessibility Committee has recommended to the council,

which is made up of general managers, that they not accept SSI as a basis for eligibility. And each time, three or four of us have made enough of a fuss that the general managers have sent it back for more consideration.

Bonney: So go back and tell me what happened at the November meeting that you referred to.

Zukas: I got there and asked Jonathan to write the following: "Is your responsibility a) to serve the interests of thousands of transit riders or b) to serve the interests of a few developers? You have thirty seconds to answer." When my name was called Jonathan and I went up to the podium, he read the statement, and Mary King, who was presiding as chair of the MTC Bay Bridge Task Force, muttered, "It shouldn't take that long."

Bonney: To whom were you addressing this question?

Zukas: The Bay Bridge Task Force.

Bonney: Was there a particular person, or the task force in general?

Zukas: In general. Well, I guess Mary King in particular, since rumor has it that she is somewhat tight with Willie Brown. As a matter of fact, I had planned in the summer to say, "How dare you to such and so," but I ran it by a couple of people and they didn't think it would be a good idea.

Bonney: Hale, you said that one way you keep people's attention and keep them interacting with you is to know more about the topic than they do or as much as they do. How do you prepare for one of these hearings, say, where you're going to testify--or in a one-on-one meeting? What do you do to prepare?

##

Zukas: Usually by calling on my accumulated knowledge. Usually my only preparation is writing a statement. For a couple of months I have been anticipating that, in preparation for the next round before the Regional Transit Coordinating Council, we probably should get some data from the Social Security Administration. But I haven't done that yet, because while I can surmise what the target will be, I haven't known for sure. We should finally find out this afternoon.

Bonney: What do you do if you're in a meeting, say a public hearing or someplace else, and you're trying to get across an idea or an opinion or convince someone to do something, and they have questions and concerns? How do you handle that?

- Zukas: Well, that rarely happens, but when it does I respond either verbally or using my board.
- Bonney: So you answer their questions directly when they come up. Is that what you're saying?
- Zukas: Yes.
- Bonney: How do you figure out who the target person is on some issues?
- Zukas: Nose around. Now, I was not wild about going down to see Liz Figueroa, because as I said in the meeting, I don't like preaching to the choir. I said this in order to lead into asking for her suggestions for who we should target--who were not members of the choir. And she gave us a couple of Republican members.
- Bonney: So how will you approach them? What will you do to approach them next?
- Zukas: I will probably tag along with the delegation. One other thing I should say is I had gone down to meet with Liz Figueroa something like a year ago, but I didn't take Nina because Mark Beckwith went, and I figured I wouldn't need to take a prominent role.
- Bonney: What role do you think your disability plays in your interactions with public officials and other people you come in contact with?
- Zukas: I suppose it allows me a form of mental jujitsu. I imagine when many people see me, they figure I am intellectually sub-par. So when I start talking things that make it clear that I'm not, it makes all the more of an impact. And besides, I'm somewhat of a spectacle. Last April I went to an ANSI meeting in Herndon, Virginia, across the road from Dulles Airport. Going to lunch one day I noticed that the local congressman had an office in the building. Now, the local congressman happens to be chair of the House Transportation Appropriations Subcommittee. So I went in and said, "If there was ever a pig in a poke, this was it." I mean, BART to San Francisco Airport.
- Bonney: So did you walk into his office and talk to him unannounced?
- Zukas: Well, he wasn't there, but I gave the message to the staff.

Bonney: So it sounds like one of the ways you have your power and your influence is that you just sort of go in and do your thing or get in their face. Would that be an appropriate expression?

Zukas: Yes.

Bonney: Let's turn our attention to a couple other things. I want to follow up on something you said in one of our earlier interviews, and that is that when you were working on the ANSI standards and working on UFAS, you said that the ANSI standards were not restrictive enough. What do you mean by the word "restrictive"?

Zukas: A better word than "restrictive" is "prescriptive." It's been a long, long, long time since I looked at that early version of ANSI. So this may not be exactly accurate, but it's close.

##

Zukas: Bathrooms shall be such as to be usable by wheelchair users.

Bonney: It didn't say what the specifics of what the accessibility were?

Zukas: No.

Bonney: I see. It just said, "Bathrooms will be accessible" and left it up to someone else to decide?

Zukas: Yes.

Bonney: Who was supposed to decide that at that point?

Zukas: The building designer.

Bonney: So they at that point would have had the freedom to decide that.

Zukas: I may be exaggerating, but not much. ANSI was somewhere around fifteen pages.

Bonney: What was the significance of the UFAS that you said was written by David Dibner?

Zukas: Under federal law there were four so-called standard-setting agencies: HUD, the General Services Administration, the Postal Service, and the Department of Defense. So each of them had their own accessibility standard. So David Dibner wrote a letter to David Stockman, who was Reagan's first director of

OMB [Office of Management and Budget], suggesting that the four agencies get together to develop one federal standard.

Bonney: Did that happen?

Zukas: Yes.

Bonney: And the federal standards then ended up being the UFAS, right?

Zukas: Yes.

Bonney: About what year was that?

Zukas: In '81, during the fight over whether or not to rescind the Minimum Guidelines and Requirements for Accessible Design, which the ATBCB had issued. Part of David Dibner's reasoning, no doubt, was that with one federal standard instead of four there was a lot less need for the MGRAD.

Mobility: A Learned Skill

Bonney: Early on you talked about when you got your first power wheelchair and what that was like. You talked a little bit about people having to learn how to use BART because they had never had the opportunity to be on public transit before that and didn't know how to use it. You used the term that mobility is a learned skill. What does that mean?

Zukas: Look at how a non-disabled child's range of mobility develops. First, they go around within the house, then around the house, then maybe around the block, and so on. My point was when an accessible means of transportation becomes available, such as BART, hordes of disabled people are unlikely to crowd onto it the day it opens. Disabled ridership will gradually grow as people learn how to use the opportunity.

Bonney: What do they need to learn? Let's say if they're going from their house to BART to get on a train. What do they have to know? What do they have to learn, other than the fact that the BART is there now and how to go where it goes? What other skills do they need before they can do that?

Zukas: They need to get comfortable with going down three blocks or whatever to BART. They need destinations. They need to have places they want to go. My theory is that the more places you go, the more places you want to go.

Bonney: So part of the issue then, if I understand you correctly, is for the person with the disability to expand their horizons of how big their world is. Is that what's happening?

Zukas: Yes. And I think my theory has been amply borne out.

Discussion of Alternative Living Options

Bonney: Hale, in one of our sessions you talked briefly about that you had thought of going into some sort kind of an alternative living situation, because finding attendants and stuff was draining and difficult, and that you would consider that if it met all of your needs. If you did that, what is required to make it satisfactory?

Zukas: The short answer is enough help and space with no burdensome restrictions.

Bonney: "Restrictions" meaning?

Zukas: As to schedule.

Bonney: You'd want to be able to come and go at will, that sort of thing?

Sprecher: Have breakfast at nine o'clock in the evening if he wants to.
[laughter]

Bonney: Does the original shared housing idea of the 1970s have merit for today?

Zukas: I can say yes even though I don't know exactly what you mean. Let a hundred flowers bloom. WID's ideal paradigm for PAS is a menu of services. The same should be true of housing options.

Bonney: Would the concept of shared housing with other disabled persons appeal to you if those needs were met and if you had the options and you could get all the attendant care you needed and you had freedom? Or is that something that sort of went away in the seventies as people moved out on their own and were successful in doing that?

Zukas: I think the development of the independent living movement brought an overemphasis--

##

Zukas: I think the development of the independent living movement brought with it an overemphasis on living on one's own. Mobility, being a learned skill, is one of the seminal truths.

I've come up with a few ideas I am really proud of. One is mobility, being a learned skill--and the other, that independent living is a truly American phenomenon with its emphasis on the individual to a degree that is to its detriment.

Bonney: Is it heresy, Hale, to talk about people with disabilities in this country living in shared housing? Is it going against the total movement?

Zukas: I think it is.

Bonney: Are these questions that we ask ourselves and talk about among ourselves but we would never say something like this in public?

Zukas: Yes.

Bonney: Do you think the future, since all of us are getting so much older, [laughter] is going to lead to some sort of shared housing concept?

Sprecher: An old folks' home. [laughter]

Bonney: With a twist.

Zukas: By the way, were you aware that Judy [Heumann] was here Saturday?

Bonney: I knew she was in town. I don't know what she's doing.

Example of Need to Continue Educating the Public

Zukas: I did not know about it until I heard her on KQED. Should I tell you about my adventure Saturday?

Bonney: Sure.

Zukas: I'm a member of the Train Riders Association of California [TRAC], and I got a notice that the board was going to meet at a restaurant in Martinez. Saturday morning Nina asked me whether I was going anyplace and I said I didn't know. I decided to take the train to Martinez.

Bonney: Is this the Amtrak train?

Zukas: Yes. Actually, California has bought \$100,000,000 of train cars and locomotives for various corridors, and this was one of those trains.

Bonney: Oh, so it wasn't Amtrak; it was a State of California train?

Zukas: Well, California contracts with Amtrak. Anyway, I get to Martinez and find the restaurant. I went a couple of blocks out of my way, I turned around, and I saw it was right across from the train station. Anyway, I kick on the door and a woman comes and says, "We're closed. Go away." So I keep kicking, and a man comes and says, "Go away." I keep kicking. He comes back. This time I hook my leg [laughter] in the door. He pointed me and he pushes me and pulls. At some point he says, "You want me to call the police?" The arm was pushed way in, which pushed the arm up like that, so the box was up by my head, which concerned me. [Description of how his wheelchair was pushed out of alignment] But anyway, I got it back down and waited. In a few minutes a cop came and there was a sign on the door saying, "TRAC". So I was in a dither. But anyway, I finally succeeded in communicating that I was a member of TRAC.

Bonney: Did they let you in?

Zukas: Yes.

Bonney: And then what did the people who had been slamming the door in your face do once you got in there?

Zukas: One thing he said was that there was a paper on my board, that he did not see my board.

Bonney: He was too busy pushing you up? [laughs]

Zukas: I don't see how it would have made any difference.

Bonney: Did the guy apologize for not letting you in and then calling the cops?

Zukas: Sort of, but I want to pursue it. I don't think he learned enough of a lesson.

Bonney: What are you going to do to pursue it?

Zukas: I'm taking suggestions.

Bonney: It's hard to believe that that kind of stuff still happens. Why do you think it happened?

Zukas: My guess is that to him I was really a spectacle. In the meeting they were talking about bills, and there's one bill that Assemblymember Don Perata introduced for Greyhound, to let them in on the feeder bus to the train.

Bonney: Let Greyhound be the company that does that?

Zukas: Yes.

Bonney: Oh God, no. [laughs]

Zukas: But then I pointed out that they were refusing to put lifts on their buses. So one of the board members said, "That's the hook we need."

Bonney: So something maybe good came out of all this.

Zukas: Yes.

Bonney: Great. We're not finished yet, right? Thank you very much for letting me come back and interview you some more. It has been really fun for me and I hope it hasn't been too hard on you. Thanks.

TAPE GUIDE--Builders and Sustainers of the Independent Living Movement in
Berkeley, Volume III

INTERVIEW WITH ERIC DIBNER

Interview 1: May 28, 1998

Tape 1, Side A	1
Tape 1, Side B	11
Tape 2, Side A	21
Tape 2, Side B not recorded	

Interview 2: June 3, 1998

Tape 2, Side B	31
Tape 3, Side A	40
Tape 3, Side B	48
Tape 4, Side A	58
Tape 4, Side B	68
Tape 5, Side A	78
Tape 5, Side B	88

INTERVIEW WITH HALE ZUKAS

Interview 1: March 5, 1997

Tape 1, Side A	96
Tape 1, Side B	99
Tape 2, Side A	101
Tape 2, Side B	104

Interview 2: March 19, 1997

Tape 3, Side A	106
Tape 3, Side B	108
Tape 4, Side A	112
Tape 4, Side B	115

Interview 3: April 9, 1997

Tape 5, Side A	118
Tape 5, Side B	121
Tape 6, Side A	123
Tape 6, Side B	126

Interview 4: April 16, 1997

Tape 7, Side A	128
Tape 7, Side B	129
Tape 8, Side A	132
Tape 8, Side B	133

Interview 5: April 23, 1997

Tape 9, Side A	135
Tape 9, Side B	138
Tape 10, Side A	140
Tape 10, Side B not recorded	

Interview 6: May 7, 1997	
Tape 11, Side A	143
Tape 11, Side B	146
Tape 12, Side A	149
Tape 12, Side B not recorded	
Interview 7: May 22, 1997	
Tape 13, Side A	153
Tape 13, Side B	156
Tape 14, Side A	158
Tape 14, Side B not recorded	
Interview 8: May 23, 1997	
Tape 15, Side A	160
Tape 15, Side B	161
Tape 16, Side A	163
Tape 16, Side B	164
Interview 9: May 27, 1997	
Tape 17, Side A	166
Tape 17, Side B	166
Tape 18, Side A	168
Tape 18, Side B	170
Interview 10: May 28, 1997	
Tape 19, Side A	173
Tape 19, Side B	175
Tape 20, Side A	177
Tape 20, Side B	178
Interview 11: January 5, 1998	
Tape 21, Side A	179
Tape 21, Side B	182
Tape 22, Side A	184
Tape 22, Side B	186
Interview 12: January 12, 1998	
Tape 23, Side A	189
Tape 23, Side B	190
Tape 24, Side A	192
Tape 24, Side B	194

INDEX--Builders and Sustainers of the Independent Living Movement in Berkeley, Volume III

Abascal, Ralph, 125, 127
 ACCD. See American Coalition of
 Citizens with Disabilities
 Access California, 66-67, 70-71
 accessibility, architectural, 23-
 25, 33, 49, 63-65, 70, 71, 83,
 86-89, 137, 140, 156, 159, 169-
 170; lawsuits, 75-77, 171, 172;
 transportation, 52, 81-82, 156,
 160-166, 169-171, 189-190
 ADA. See Americans with
 Disabilities Act
 ADAPT. See American Disabled for
 Accessible Public Transit. Now
 called American Disabled for
 Attendant Programs Today
 Addus, 134
 advocacy, for barrier removal,
 65; political, 177, 178. See
 also Center for Independent
 Living
 AFL-CIO-CLC, 150
 Agran, Larry, 125, 127
 Aid to the Totally Disabled, 123
 Air Carrier Access Act, 78
 Alameda-Contra Costa County
 Transit Board, 164
 Alameda County Public Authority,
 128-129
 Alpha One (ILP), 74-77
 American Coalition of Citizens
 with Disabilities, 161
 American Disabled for Accessible
 Public Transit, 164
 American National Standards
 Institute, 159, 164, 165, 191,
 192
 American Public Transit
 Association, 161, 162, 164
 Americans with Disabilities Act,
 77-78, 87, 162, 163, 164, 172
 Amyotonia Congenita, 3-4

ANSI. See American National
 Standards Institute
 Antioch College West, 67
 APTA. See American Public Transit
 Association
 Architectural and Transportation
 Barriers Compliance Board,
 143, 160, 162-167, 177, 193
 architectural barriers. See
 accessibility
 Architectural Barriers Act, 158
 Arnett, Dixon, 127
 Assembly Bill 204, 176
 assistive devices, 26, 191, 196
 assistive technology, 76, 78;
 reach and ramp concept, 26
 Assistive Technology Act, 78
 ATBCB. See Architectural and
 Transportation Barriers
 Compliance Board.
 ATD. See Aid to the Totally
 Disabled
 attendants, 7, 13, 40-43, 50-51,
 81-82, 89, 102, 135;
 background/fingerprint checks,
 129-130; for Greg Sanders, 49;
 for Hale Zukas, 49-52, 57; for
 John Hessler, 4, 13, 16-17, 32;
 for Phil Draper, 49; for Scott
 Sorenson, 3-4, 18-22, 27, 32;
 "personal care option," 133;
 registry, 129-130; training,
 130-131, 157; unionizing, 131,
 135; wages, 11-12, 132

 Baez, Joan, 106
 Baker, Bruce, 168
 Baptiste, Gerald, 68, 72
 BART. See Bay Area Rapid Transit
 BART Access Coalition, 171
 BART Accessibility Task Force,
 170, 172

- Bates, Tom, 176
- Bay Area Outreach Recreation Program. See Berkeley Outreach Recreation Program
- Bay Area Rapid Transit, 52, 170-172, 193
- Bay Bridge Task Force, 189-190
- Beckwith, Mark, 189, 191
- Beilenson, Anthony, 127
- Berkeley, California, 120-122; community development funds, 63; counterculture, 4-6, 19; disability compliance coordinator, 84-85; housing committee, 48-49; mayor's task force on people with disabilities, 72-73, 85; rent strike, 20
- Berkeley Commission on Disability, 85, 87, 172
- Berkeley Historical Society, 121, 137
- Berkeley Neighborhood Traffic Plan, 140-141
- Berkeley Outreach Recreation Program, 69
- Berkeley Tenants Union, 22, 48
- Biscamp, Larry, 7, 13, 15, 46, 174. See also Rolling Quads
- Black Panthers, 148. See also Rehabilitation Act of 1973, 504 demonstration
- BORP. See Berkeley Outreach Recreation Program. Now called Bay Area Outreach Recreation Program
- Bowe, Frank, 153. See also Rehabilitation Act of 1973, 504 demonstration
- Brean, Edna, 6
- Breslin, Mary Lou, 144, 145
- Bromley, Martha, 179, 180
- Bruyn, Henry, 10
- Burton, John, 124, 127
- Burton, Phil, 124
- Butcher, Catherine, 108
- Califano, Joseph, 146, 152, 154, 167. See also Rehabilitation Act of 1973, 504 demonstration
- California, 1991 budget crisis, 133
- California Association of the Physically Handicapped, 66
- California College of Arts and Crafts, 71
- California State Department of Rehabilitation, 13, 16, 70, 106-108, 114, 116
- California State Health and Welfare Agency, 133
- California State Polytechnic College, 97
- California State Senate Finance Committee, 125; Health and Welfare Committee, 125, 127
- Camarillo State Hospital, 47
- Campus Committee for the Removal of Architectural Barriers. See Coordinating Committee to Remove Architectural Barriers, UC Berkeley
- Cannon, Dennis, 161, 162, 164, 166
- Carter, James Earl, 159, 160, 165
- CBO. See Congressional Budget Office
- Center for Independent Living, Inc., 51-55, 59, 63-64, 67-70, 88, 112, 121, 135, 143, 144, 156, 168, 169, 173, 174, 175, 176, 188; community affairs coordinator, 135, 137, 143; deaf services at, 68, 83-84; establishment of, 45-47, 52-54, 57, 118-120, 122, 136; grants, 119, 120, 136, 137; housing department, 63-64; incorporation, 120, 135; organizational issues, 55-63; sexism at, 59; strike, 56-57, 70; youth program, 68-69
- cerebral palsy, 97, 161
- Chavez, Phil, 69
- Chris Jespersion School, 97-98, 100, 104, 179

- CIL. See Center for Independent Living, Inc.
- civil rights movement, comparisons with disability rights, 60
- Cleland, Max, 159
- Cleveland Amendment, 161, 162, 163
- Cohelan, Jefferey, 112-113
- Collignon, Frederick (Fred), 46, 54
- Collins, Carter (C.C.), 29
- Committee for the Removal of Architectural Barriers. See Coordinating Committee for the Removal of Architectural Barriers.
- Common College, 32
- Community Development Block Grant. See Center for Independent Living, grants.
- Cone, Curtis (Kitty), 144, 161, 183
- Congressional Budget Office, 160-161
- Coordinating Committee to Remove Architectural Barriers, UC Berkeley, 34-36
- Cotkin, Kalya, 47, 63
- Cowell Hospital Residence Program, UC Berkeley, 3-16, 108
- CP. See cerebral palsy.
- Craig, Roger, 167
- Cranston, Alan, 153, 154, 155, 158, 164. See also Rehabilitation Act of 1973, 504 demonstration.
- curb cuts/curb ramps, 24-26, 66, 120-122, 135, 139-142; design, 85-86, 140-141
- cross-disability inclusion, 61, 140
- Dabel, Bill, 140
- Dahl, Dale, 84
- deaf services, 68, 83-84
- DeLeuw, Charles (Chuck), 140
- Dellums, Congressman Ronald V., 113, 179
- Department of Health, Education and Welfare, U.S., 121-122, 137, 146, 188; Section 504 regulations, 161
- Department of Vocational Rehabilitation. See California State Department of Rehabilitation.
- Dibner, David, 165-166, 192-193
- Dibner, Eric, *Interview* 1-91; education, 2, 4-6, 12, 18, 67; interests and development, 28-29, 47, 52; 107, 121-122, 126, 137, 142, 156, 182-183
- Dibner, Om Devi, 29, 73-75
- disability: alternative living options, 194-195; childhood experiences with, 97-99; communication and, 101-102; diagnosis and progression, 99-100; establishing independence, 40, 61, 101, 157; experiences with discrimination, 105, 196, 197; family response and reaction, 98-101, 185, 186; learned mobility skills, 193-195; reflections on, 1-2, 14, 88-91, 176, 177, 178 186, 187 194, 195, 196
- Disability Law Research Center, 67, 70, 71, 143, 144
- disability rights movement, 15, 56, 59-63, 83-84, 88-91; civil rights, 60-63; leadership role in, 59-63, 177, 178, 189-192; political action, 61
- Disability Rights Education and Defense Fund, 68
- Disabled and Blind Action Committee, lobbying efforts of, 123, 124, 125; political action, 138. See also Center for Independent Living.
- Disabled Students Program. See Physically Disabled Students Program, UC Berkeley.
- DLRC. See Disability Law Research Center.

- Donald, James (Jim), 13. See also Rolling Quads.
- DOT. See United States Department of Transportation.
- DR. See California State Department of Rehabilitation.
- Drake, Dan, 66
- Draper, Phil, 49, 114, 119, 123, 170
- DREDF. See Disability Rights Education and Defense Fund.
- Dresher, Paul, 19
- Duncan, Scott, 167
- E&J's. See Everest & Jennings Company.
- Easy Does It (emergency service), 43
- education, admission to mainstream schools, 104-105
- Education for All Handicapped Children Act, 105
- Enders, Alexandra (Sandy), 69
- environmental disability. See multiple chemical sensitivity.
- Everest & Jennings Company, 114
- Fair Housing Act, 78
- Fair Housing Amendments Act, 78
- Fantin, Dennis, 37
- Federal Architectural and Transportation Barriers Compliance Board, 158
- Feinbaum, Sandra (Sandy), 69
- Ferrerya, Nancy, 72
- Fewell, Carol, 37
- Figueroa, Elizabeth (Liz), 189, 191
- Florence and Worden McDonald Award for Community Service, 179, 181
- Food Conspiracy, 31-32
- Fortini, Mary Ellen, 121
- France, travel in, 16-17
- Free Speech Movement, 106
- Fuss, Michael, 37, 118
- General Services Administration, 165
- George, John, 112, 113
- Golden, Marilyn, 66-67, 162-164
- Gorman, Walter, 29, 47, 52
- greenhouse, the, 28-32, 49, 52
- Greyhound busline, 197
- Grimes, Charles (Chuck), 37-38, 114, 116
- Grimes, Ruth, 23, 46
- Grunsky, Donald, 125
- GSA. See General Services Administration.
- Hancock, Loni, 72, 156
- HCFA. See Health Care Financing Administration.
- Health Care Financing Administration, 133
- Hessler, John, 4, 7-8, 16-17, 19, 24, 26, 29-30, 32, 37-38, 41, 45-46, 110-111, 118
- Het Dorp Village, 88
- Heumann, Judy, 46, 59, 69, 105, 112, 138, 144, 146, 158, 173, 175, 195
- HEW. See Department of Health, Education and Welfare, U.S.
- Hiserman, Mary Ann, 26, 34, 36, 72
- Hockenberry, John, 88
- Homemaker Chore Program. See In-Home Support Services.
- Hotchkiss, Ralf David, 152, 155, 158, 176
- housing discrimination, 44
- IHSS. See In-Home Support Services.
- independent living centers, 57, 74-77, 79
- independent living movement, 79, 81, 194, 195. See also Center for Independent Living, disability rights movement.
- Independent Provider [IP], 134

In-Home Support Services, 126,
128, 129, 131-134, 189; HR1,
1972, 123-124

institutionalization, 47

International Association of
Machinists and Aerospace
Workers, AFL-CIO-CLC, 150

Jackson, Chuck, 148, 152. See
also Rehabilitation Act of
1973, San Francisco sit-in.
Jespersen, Chris, 97. See
also Chris Jespersen School.
Joe, Tom, 121, 136, 188

Kaiser, Jean, 65-66
Kaplan, Deborah, 152, 155, 158
Kennedy, Jae, 133
King, Martin Luther, Jr., 60
King, Mary, 190
Kirshbaum, Hal, 67
Konkel, David, 37

Lacy, Johnnie, 67
Langdon, Lawrence (Larry), 7,
118. See also Rolling Quads.
Leech, Peter, 53, 68
Lehr, Bronson, 43
Leibowitz, Herbert (Herb), 46,
136

Lennox, Andrew (Andy), 37
Levy, Lesley, 171
Lewis, David, 161
Lifchez, Raymond (Ray), 34, 54,
88

Litvak, Simi, 121
Lomax, Brad, 148, 152. See also
Rehabilitation Act of 1973, 504
demonstration; Black Panthers.
Lorence, Donald, 38
Los Angeles Times, 112

MacArthur Fellowship Foundation,
John D. and Catherine T.,
award, 176

Mace, Ron, 70

Mahoney, Eddie. See Money, Eddie.

MAHP. See Maine Association of
Handicapped Persons.

Maine, 1-2, 18, 22-23, 57, 73-74,
79; transportation access in,
81

Maine Association of Handicapped
Persons, 75-76

Maine Human Rights Act, 78

Maldonado, Joseph, 146, 147. See
also Rehabilitation Act of
1973, 504 demonstration.

Malm, F. T., 107

Mankin, Michael, 34

Marsh, Jonathan, 189, 190

McEwen, Jan. See McEwen-Brown,
Janet.

McEwen-Brown, Janet, 119

Medicaid, 132-133; trainings in
New Mexico, 79

Medi-Cal, 21, 114, 115, 116

Metropolitan Transportation
Commission, 170, 190

MGRAD. See Minimum Guidelines and
Requirements for Accessible
Design.

Miller, George, 124

Minimum Guidelines and
Requirements for Accessible
Design, 160, 165, 166, 193

MIUSA. See Mobility International
USA.

Mobility International USA, 70

Money, Eddie, 31

Moscone, George, 124, 127

MTC. See Metropolitan
Transportation Commission.

multiple chemical sensitivity,
83-84

Myers, Judy, 82-83

Nandi, Jean, 172

National Federation of Home
Makers, 40

National Home Care. See Addus
National Labor Relations Board,
56.

- NLRB. See National Labor Relations Board.
- New Mexico, 76-84; Governor's Committee on Concerns for the Handicapped, 82; Healthy Housing Coalition, 83-84
- New Mobility, 135
- Newsome, Karen Topp. See Topp, Karen.
- New Vistas, 79
- Nixon, Richard, 46, 113, 122-123, 137
- Northern California Residential School for Cerebral Palsy, 97, 100, 102, 104
- Oakland, California, city of, 65-67
- Oakland Tribune, 178
- occupational therapy, 101, 180
- Office of Management and Budget, 193
- O'Hara, Susan, 26, 64-65
- OMB. See Office of Management and Budget.
- Om Devi. See Dibner, Om Devi.
- Origins and History of Our Institutional Models, The*, 47
- OT. See occupational therapy.
- Pachovas, Michael, 72, 85
- paratransit, 160, 162. See also accessibility, transportation.
- PAS. See personal assistance services; attendants.
- PCSP. See Personal Care Services Program.
- Pechen, James (Jim), 144
- Pedro, Linda, 82
- peer counseling, 39-44
- Perata, Don, 197
- Perlman, Itzhak, 88
- Perotti, Linda, 9, 29, 63
- personal assistance services, 177, 187, 194. See also attendants
- Personal Care Services Program, 133
- PDSP. See Physically Disabled Students' Program.
- Physically Disabled Students' Program, UC Berkeley, 15, 23-24, 27-30, 32-46, 49, 110-114, 118-119, 121, 135-136, 173; advisory board, 111; Career Planning and Placement Office, 144; residence hall, 111
- political affiliation, 100, 159, 187
- Postal Service, U.S., 165; Postal Union, 167
- Raggio, Jim, 163
- Ramparts magazine, 112
- Reagan, Ronald W., gubernatorial administration, 125, 127; presidential administration, 160, 163, 166, 192
- Regional Transit Coordinating Council Accessibility Committee, 189, 190
- Reeve, Christopher, 88-89
- Rehabilitation Act of 1972, 122, 137
- Rehabilitation Act of 1973, San Francisco sit-in, 6, 143-150, 153-156; Section 502, 158; Section 504, 46, 77; Section 504 implementation, 87; trainings, 67, 70, 76; Washington trip, 149-155
- Rehabilitation Services Administration, 46, 69, 119, 136
- Rein, Paul, 66
- residence hall. See Physically Disabled Students' Program.
- Reynolds, Esther. See Dibner, Om Devi.
- Reynolds, William Bradford, 166-167

Roberts, Edward V., 7-8, 28-29, 31, 32, 46, 51, 53, 112, 119, 121, 123, 156, 173-176; CIL executive director, 57-59, 174-176

Roberts, Mark, 32

Roberts, Randy, 29

Roberts, Ron, 31

Roberts, Zona, 13, 17, 23, 27-29, 31-32, 45, 47

Rolling Quads, 13-15, 110

Rosewater, Ann, 153. See also Rehabilitation Act of 1973, Section 504.

Rosen, Linda, 121, 122, 139

Rosenberg, Bob, 127

Russian language, 107; work as translator, 108

Sanders, Greg, 49

San Francisco, 132, 133, 138; Opera House, 64-65

San Luis Obispo, 97, 98, 104

Santa Fe, New Mexico. See New Mexico.

Santos, Richard (Dick), 174

satellite television, in community colleges, 78

Schechter, Diane, 69

Scheer, Robert, 112

Section 504. See Rehabilitation Act of 1973.

SEIU. See Service Employees International Union.

Service Employees International Union, 42, 129, 134

sexist attitudes, 59

shared housing. See disability, alternative living options.

Shnaider, Renah, 65

Smith, Eleanor, 9

Sorbonne, lack of accessibility at, 17

Sorenson, Scott, 3-4, 7-8, 16, 18-22, 32

speech impairments, communication training and, 87

Sprecher, Nina, 96, 168, 174, 183, 191, 195

SSI. See Supplemental Security Income.

SSP. See State Supplemental Payment.

State Supplemental Payment, 124

Stein, Kenneth Erwin, 53-54, 66, 85, 147, 169

Steiner, Ann, 71, 85

Stone, Sandy. See Feinbaum, Sandra.

Supplemental Security Income, 123, 126, 156, 189, 190

Sygall, Susan, 14, 69-70

Syracuse University, 47

Taylor, Judy, 118, 120

Technology Related Assistance Act for Individuals with Disabilities, 76

therapy, impact on self-esteem, 98

Topp, Karen Goodwyn Newsome, 9, 175

Train Riders Association of California, 195, 196

TRAC. See Train Riders Association of California.

TransBus, 163, 164. See also accessibility, transportation.

transportation, accessible. See accessibility, transportation.

Transportation and Access Community Affairs Committee, 156

Twigg, Sally, 180

UFAS. See Uniform Federal Accessibility Standard.

Uniform Federal Accessibility Standard, 166, 192

United Airlines, 150

United Domestic Workers. See Addus.

United States Department of
Transportation, 161, 163, 164,
170
University of California,
Berkeley, 2-3, 106-109; UC
Extension, 106. *See also*
Coordinating Committee to
Remove Architectural Barriers;
Cowell Hospital Residence
Program; Physically Disabled
Students' Program, UC Berkeley.
Urban Institute National Study,
168, 169

Vietnam War, 110; demonstrations
against, 6, 188, 189
Vocational Rehabilitation,
Department of. *See* California
State Department of
Rehabilitation.

Wangeman, Matthew, 109
Wanning, Tom, 148
Wasserman, Barry, 142
wheelchair, first use, 103, 104;
power wheelchair, 11-12, 114-
116
Wheelchairs of Berkeley, 68
Wheeled Mobility Center, 176
white cane laws, 77
White, Evan, 150
WID. *See* World Institute on
Disability.
Williams, Arleigh, 107
Williamson, Dale, 136
Willsmore, Herbert (Herb), 27,
114, 118, 120, 123
Winter, Michael, 56
Wittman, Fried, 52-54
Wolf, Jerry, 63, 66
Wolfensberger, Wolf, 47n
Woods, Tom, Jr., 130
World Institute on Disability,
121, 133, 174, 179, 194
Wright, Frank Lloyd, 28
Wright, Patrisha, 67

Zirlin, Julie, 71
Zola, Irving, 88
Zukas, Bronislaus, 96-97, 99,
102-105, 181
Zukas, Hale, *Interview* 96-197;
24, 27-28, 48-52, 57, 61, 63,
85-86; education, 103-109;
interests and hobbies, 181-185
Zukas, Helen, 96, 98-99, 103-105,
114-115, 157, 180, 182, 185

SHARON BONNEY

Interviewer/Editor

Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

Sharon Bonney received a B.S. in Communication and Journalism from the University of Illinois and an M.A. in Public Affairs from the University of Iowa. After working as a reporter and freelance writer, she established the Services for Handicapped Students Office at Iowa before working in the Department of Rehabilitation as a client advocate in Tennessee.

In 1979, Ms. Bonney became director of the Physically Disabled Students' Program at UC Berkeley for nine years. She later was the assistant director for the World Institute on Disability. For the past two years, she has been an interviewer/editor for the Regional Oral History Office at UC Berkeley for the Disabled Persons' Independence Movement Project.

Her professional activities include numerous publications on disability issues; founding member, president, treasurer, and conference chair of the Association on Handicapped Student Service Programs in Post Secondary Education (now known as AHEAD); participant in the White House Conference on Handicapped Individuals; and current member of the Society for Disability Studies.

Ms. Bonney has muscular dystrophy and is a wheelchair user.

KATHRYN COWAN

Interviewer/Editor

Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

B.A. in Communications from California State University Hayward.

In the 1980s, she was a job developer for a disadvantaged youth organization. She developed a program that brought youth together with senior citizens who served as mentors by sharing their personal and work histories.

She has a long-standing interest in political and social change, and followed closely the civil rights, anti-war and women's movements. In the early 1990s she became interested in the disabled persons' independence movement. In 1995 she was diagnosed with muscular sclerosis.

She is currently the librarian for HomeBase, the Center for Common Concerns, a public interest law firm that develops and supports policies and programs to reduce and eliminate homelessness.

In 1997 she joined the staff of the Regional Oral History Office, The Bancroft Library, University of California, Berkeley, as an interviewer and editor for the Disability Rights and Independent Living Movement oral history series.

PANC
MSS
2001/49
C
v.3

U. C. BERKELEY LIBRARIES



068216619

